

***Intimate Relationships and Sexuality for Adults with an Intellectual
Disability: Exploring the views of Adult Intellectual Disability Service
Providers and their Staff members.***

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Declaration

I hereby declare that this project is entirely my own work, other than the counsel of my supervisors. The work herein has not been submitted as part of another degree at the University of Limerick or any other academic institution.

Andrew Deffew

Date: 15th April 2019

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Abstract

Introduction: Research suggests that people with an intellectual disability (PWID) have historically been suppressed in their expression of relationships and sexuality. Adult ID service structures, staff member's attitudes and PWID's family viewpoints have been reported to influence this suppression. In Ireland, three other factors are noteworthy; a restrictive legislative framework; a conservative culture influenced by religion; and the adaption towards the biopsychosocial model of care and advances in Special Needs Education. This current study aims to explore the current attitudes and views of Irish Adult ID service providers and their staff on PWID's expression of relationships and sexuality.

Method: A mixed methods design was employed. During the quantitative phase, staff (n=86) completed an online survey to assess their 'attitudes to sexuality' relating to PWID. Meanwhile, qualitative methods were utilised to analyse Adult ID service provider 'Relationship and Sexuality' policy documents (n=5). These methods were also used to analyse staff participants open-ended questionnaires (n=86).

Findings: Thematic Analysis was applied to the 'Relationship and Sexuality' policy documents and staff open-ended questionnaires. Five themes were generated from the policy documents; *'Rights of PWID'*, *'Values'*, *'Training and Educational Supports'*, *'Welfare and Protection'*, and *'Supportive Structures'*. Policies were interpreted to contain mixed messages on these themes, while also providing a dominant reference towards the protection of PWID. Three themes generated from the questionnaire; *'Unsupported and Frustration'*, *'Taboo Subject Matter'*, and *'Vulnerability and Access to Education'*. Participants reported a lack of service supports, dominant conservative viewpoints and PWID vulnerability. Staff 'attitudes to sexuality' were reported to be affected by demographic factors of age, education, practising religion and reading of service policy.

Discussion: This study provided a comprehensive current account of Adult ID service provision regarding relationships and sexuality in Ireland. It highlighted the need for updated service policy, improved service practices, and enhanced provisions for staff and the PWID that they support. Implications for future research and clinical practice are also discussed, in terms of improvements in education, training, and the need for increased discourse on the subject matter.

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Chapter One – Introduction

“A culture is not an abstract thing. It is a living, evolving process. The time is to push beyond standard-setting and asserting human rights to make those standards a living reality for people everywhere”.

Mary Robinson, former President of Ireland, and former UN Commissioner for Human Rights.

1.1 Overview of the Present Study

In early 2012 in a drama hall in Galway, a group of people with an Intellectual Disability (PWID) collectively known as the ‘Blue Teapot Theatre Company’ performed their play ‘Sanctuary’. The play depicted a couple, both of whom had an ID and attended their local Adult ID day service. It told the story of a scheduled group day trip to the cinema where the couple had their own agenda, to diverge from the group to a nearby hotel to have sexual intercourse. The play satirically looked at the resulting fallout. It detailed the conversations between the couple and a staff member who was reluctant to help them with their plans. The staff explained his reluctance was due to the potential legal repercussions that both he, and the couple could face. The show, which was layered with genuine warmth tackled the restrictions that were imposed on PWID under Section 5 of the Criminal Act (1993) legislation in Ireland. From these humble beginnings, this play became the subject of a televised ‘making of’ documentary on the Irish national broadcaster and was later developed into a big screen production for which it received national acclaim. Most importantly, it drew the national spotlight on Section 5 legalisation and framed the question of its repeal firmly around PWID’s equality and human rights. This humble theatre company from Galway played a significant role in the subsequent change in the legislation in March 2017.

However, systems and culture take time to change. Under the backdrop of such long-standing practices and guidance, service providers and staff can be slow to move and put these changes into action. It was with this understanding that the idea to explore this subject area was born. From initial consultation with Senior Clinical Psychologists, my supervisor and a review of the disseminated literature the idea for this research took formation. It was felt that it was important to evaluate current service provider’s practices, and also investigate staff member’s current viewpoints in their services.

For this achieved, three areas would be investigated. Firstly, Adult ID service provider’s policy documents would be critically analysed to explore their delivery on relationships and

sexuality for PWID. Research would critically explore their policies' messages of support and/or restrictions, and whether these policies reflected the changes of the 2017 legislation. Secondly, there would be an evaluation of staff attitudes on this issue. This evaluation would be reviewed in reference to key staff demographic features of age, gender, religious practice and staff education levels. Thirdly, the research would investigate staff member's current opinions and beliefs on the provision of relationships and sexuality for PWID in Adult ID services. Taken together these aims will provide a current audit of Adult ID service provision in Ireland and add to the relevant literature. This research will also help improve service providers and their staff in making the necessary changes to their practices for the best interest of PWID.

The initial concept for the study included the views of the general public. It was thought that this would broaden the parameters of the study and stimulate the public's thought processes and preconceived ideas on this issue. It was also thought that this would improve services understanding on these issues as they push for more PWID inclusion and involvement in the community. However, one service provider had a distinct issue with the inclusion of the public and asked for its removal. This will be discussed further in the Methodology and Discussion chapters. As a result, the focus of the study was exclusively on the service providers and their staff members.

On a personal level, as a third-year Trainee Clinical Psychologist, currently working in a Specialist Adult ID service, I hold a particular interest in this area. I have for many years before training, worked as an Assistant Psychologist in these services, and I have witnessed first-hand organisations and staff either ignore, restrict, and less frequently support relationships and the sexual expression of PWID. With such inconsistencies, I personally felt that it was important to increase the dialogue for both organisations and staff around this issue.

1.2 Thesis Structure

Chapter Two will begin with defining intellectual disability. Chapter Three will detail the existing literature on PWID and intimate relationships and sexuality. Chapter Four will outline the methodology process used in this study, both data collection and analysis. Chapter Five will describe the results of this study. It will outline both the quantitative and qualitative findings. Chapter Six will review the salient themes of the study in the context of the literature review presented in Chapter Three. It will discuss the strengths and limitations, while also recognising the potential for future recommendations in policy and clinical practice.

1.2.1 Chapter Two: Definition

This short chapter outlines the definition of Intellectual Disability using current diagnostic criteria.

1.2.2 Chapter Three: Literature Review

This chapter details the search methods used to gather the relevant literature for this study. It outlines the relevant findings from the literature concerning intimate relationships and sexuality for PWID. It considers the influences of historical restrictions and Irish cultural and legislative factors. It then discusses the impact of service provider guidance, family viewpoints, staff attitudes and service structures and how these interact with the construction and perception of the intimate relationships for PWID. The chapter closes with the present study's research aims.

1.2.3 Chapter Four: Methodology

This chapter will outline the researcher's rationale for the study. It discusses the research design and methodology framework that was selected. It refers to the sampling methods used, and the participants recruited. The chapter will detail the significant ethical barriers that were imposed by service providers on the initial research question and the resulting changes that were required to make the study feasible. The concluding section looks at the procedures employed during data collection and gives an outline of the data analysis techniques used.

1.2.4 Chapter Five: Results

This chapter will outline the results from the qualitative review of Adult ID service 'Sexuality and Relationship' policy documents and the completed staff surveys. It will broadly be divided across three sections. Firstly, it will report on the analysis of the policy documents, exploring the themes that were developed from the data. The second section will report on the results of the survey's 'Attitudes to Sexuality' questionnaire. The final section will consider the themes that developed from the open-ended survey questions.

1.2.5 Chapter Six: Discussion

Chapter Six will discuss the salient findings that emerged throughout the course of the study. These findings will be linked with the literature review presented in Chapter Three. It will then discuss the strengths and limitations of the study, while also recognising the potential for future recommendations in policy and clinical practice.

Chapter 2. Definition

2.1 Intellectual Disability

An intellectual disability (ID) is an intellectual impairment that has been evident from the developmental period in life. People with an Intellectual Disability (PWID) can experience significant issues in terms of their overall functioning. They may experience deficits in terms of their reasoning, learning, problem-solving and generally in their day-to-day adaptive functioning (World Health Organization, 1992). An ID is sub-categorised through four separate IQ ranges, from mild, 69-52; moderate, 51-36; severe, 35–20; to profound, 19 or below. These standardised IQ scores are recommended to be used as a guide rather than applied rigidly. The figure beneath by the American Psychiatric Association - APA (2013) represents both the range of intellectual disability from mild to profound and the subsequent support needs that might be associated with each range. It also demonstrates the associated deficits in adaptive functioning that PWID can experience in the areas of daily living skills, communication, socialisation and conceptual domains. These associated difficulties in cognitive and adaptive functions can negatively influence PWID's acquisition and retention of knowledge and skills (Schaafsma, Kok, Stoffelen, & Curfs, 2015). This study will relate to the people that meet this outlined profile of cognitive and adaptive deficits which have been evident from their developmental period in life.

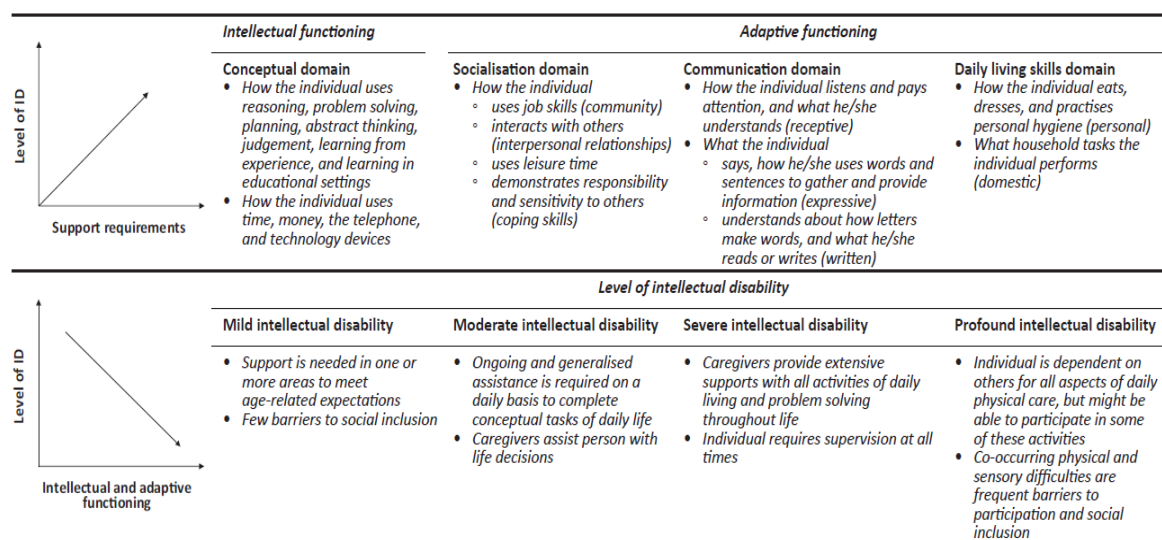


Figure 1. Continuum of support needs according to severity of intellectual disability

Source: American Psychiatric Association (APA), 2013, Diagnostic and statistical manual of mental disorders, 5th edition: DSM-5, American Psychiatric Association, Arlington, TX. ID, intellectual disability.

Chapter 3. Literature Review

3.1 Literature Search Strategy

Published articles relevant to the subject topic were identified through a comprehensive search of the following databases: PsychInfo, PsychArticles, Embase, Web of Science, Cochrane Database and Google Scholar. Potentially relevant search items identified from the literature were searched for within these databases to identify relevant published articles. Combinations of the following search items were used: Intellectual Disability and relevant variants (*Intellectual Impairment, Intellectual Handicap, Developmental Disability, Learning Disability and Mental Retardation*), Staff and Service Providers (*Care staff, Frontline Staff, Social Support, Nursing, Intellectual Disability Services, Service Providers*), Structures (*Policy/Policies, Guidelines, Education, Training, Organisation, Rules*), Sexuality (*Intimate Relationships, Sexual Behaviours, Sexual Education, Homosexuality, Heterosexuality, Sexual Orientation, Masturbation and Sexual Relationships*), Attitudes (*Opinions, Beliefs, Judgements and Views*). From these search results, titles and abstracts were reviewed for further reading and critiquing. The reference lists from these papers were reviewed, and the relevant papers to the subject area were subsequently identified and reviewed.

3.2 Intimate Relationships and Intellectual Disability

The ability to form personal and sexual relationships has been strongly linked to positive wellbeing and happiness (World Health Organization, 2015). However, historically for the majority of PWID, the ability to form these relationships has been limited. Traditionally, PWID have been largely isolated from the rest of society. They lived in segregated institutional type settings with little to no interaction with the wider community (Health Service Executive, 2011). Coupled with this segregation, there was a negative perception of PWID and intimate relationships (Craft & Brown, 1994). PWID were seen as unable to explore their sexuality through a healthy means (Kelly, Crowley, & Hamilton, 2009). They were characterised as either being the “eternalised child”; asexual, uninterested and unconcerned about their sexuality (Aunos & Feldman, 2002; McCarthy, 1999). Alternatively, they were considered to be hypersexual; sexually obsessed, engaging in excessive masturbation, and perpetrators of sexually inappropriate and/or abusive acts (Craft & Craft, 1981; Wilson, Parmenter, Stancliffe, & Shuttleworth, 2011). As a result of these perceptions, PWID in these institutional settings were subject to large scale policies of forced sterilisation and imposed restrictions on personal and sexual relationships (Craft & Craft, 1981).

3.2.1 “Normalisation” and PWID’s Sexual Expression

In the 1970s Wolfensberger’s philosophy of ‘Normalisation’ came to prominence (Valenti-Hein & Choinski, 2016). Normalisation looked to challenge the many years of institutional segregation that PWID had endured by advocating for their human rights. It campaigned for PWID’s position within society by advocating for independence, choice, and inclusion and promoting their human rights by offering “cultural normativeness” (Rushbrooke, Murray, & Townsend, 2014). The philosophy supported PWID to have the same opportunity for life experiences as those in general society; for example, accommodation, employment, education and recreation (Gilmore & Chambers, 2010). ‘Normalisation’ lay the foundation for the process of de-congregation from institutional type settings towards more community-based accommodation and general inclusion in society (Health Service Executive, 2011). The philosophy delivered a progressive shift in ideology about the rights of PWID within society. As a direct result, the pursuit of autonomy and sexual rights for PWID also progressed forward (Aunos & Feldman, 2002). Recent studies note that service providers, their staff and the general public have become more progressive towards PWID’s sexual identity (Cuskelly & Bryde, 2004; Healy, McGuire, Evans, & Carley, 2009). However, research continues to acknowledge that this identity is still restricted (Brown & McCann, 2018; Ćwirynkalo, Byra, & Żyta, 2017). It is documented that society still holds a very protective stance about PWID’s expression of sexuality (Hollomotz, 2009; McCarthy, 1999; Rushbrooke et al., 2014).

3.2.3 PWID’s Interest in Sexuality and Relationships

It is important to note that PWID are very much interested in sexuality and intimate relationships. Studies with PWID have found that their desire to have an intimate relationship has been a key theme of their analysis (Bane et al., 2012; Sullivan, Bowden, McKenzie, & Quayle, 2013; Wilkinson, Theodore, & Raczka, 2014). In Gil-Llario, Morell-Mengual, Ballester-Arnal, and Díaz-Rodríguez (2018) study of 360 male and female PWID, they found that 97.8% of them were interested in sexuality and relationships. While 93.3% of male ID and 85.6% female ID reported that they wanted to have more discussions on the topic of sexuality. Likewise, Brown and McCann (2018) report that PWID have a desire to have meaningful relationships. In their review, they highlight that PWID have a desire to have both friendships and intimate relationships. In Irish research on the area, Healy et al. (2009) found that PWID show a clear understanding of companionship and relationships, while they also recognised the positive effect that these relationships had on their self-esteem. This study also detailed that

PWID aspire to be married and have children. It is therefore recognised that PWID have the same needs and desires as the general population (Fulford & Cobigo, 2018). As such, they require the same means to express their sexuality freely.

3.3 Irish Context

The impact of social and political factors on PWID lives needs to be recognised (Brown & McCann, 2018). In Ireland, there are three areas that affect the expression of sexuality and intimate relationships for PWID that perhaps do not affect other countries to the same level; they are religion, Irish legislation and the changes in service models of care and advances in Special Needs Education. Addressing these three areas are fundamental to understanding the backdrop of intimate relationships for PWID in Ireland.

3.3.1 Religion in Ireland

In the early and mid-twentieth century, religion had a significant role in Irish society. From the patronage of primary and secondary education to the altar sermons at mass, the Catholic church played a central role in shaping the minds of Irish citizens on all life decisions (Brown, 1981). The Catholic church provided the bastion for Irish moral standards, and its influence was far reaching. The prominence of this position was evident by its dominant position being enshrined in the 1937 Irish constitution (Lee, 1989). These are important factors to review when we consider Catholicism's view on sexual relationships. For example, the Catholic church's views on sexual acts outside of marriage, abortion, homosexuality, and use of contraception. Indeed, Social Historians note that "Catholic Ireland" was sexually restrictive and remained so for many years (Ferriter, 2004). For example, it was only in 1985 that contraception (condoms without a prescription) were freely allowed to be purchased, while homosexuality was only decriminalised in 1993, Playboy magazine sold for the first time in 1995, while abortion up to 12 weeks only became legislated into Irish law in early 2019. It is contended that the prominent role of the Catholic church and its conservative influence on Irish society cannot be under-emphasised. Even today, although those practicing Catholicism has decreased, owing to a younger population, immigration and urbanisation (Healy et al., 2009; McConkey & Leavey, 2013), recent 2016 census recordings show that 78.3% of the population still identify as Roman Catholic (Central Statistics Office, 2016). As such, Catholic teachings and practices were and continue to be very much part of the Irish social fabric.

3.3.2 Religion and PWID in Ireland

For PWID in Ireland, the Catholic church had a very central role. Religious orders staffed and owned the institutional settings where PWID would have lived (Healy et al., 2009). These service providers would have promoted restrictive standards which would have suppressed relationships and sexual expression in this population (Gardiner & Braddon, 2009; Healy et al., 2009). It is noted that the Catholic church's involvement in day-to-day service provision has decreased over the last few years (Evans, McGuire, Healy, & Carley, 2009; Healy et al., 2009). This has primarily been diluted by changes in staffing from non-religious backgrounds to other professions, for example, nursing and social care workers. However, some service providers in Ireland still hold strong religious attachment. Service providers are seen to retain religious names, the Catholic church still owns their lands and dwellings, religious iconography still hang on their walls, and members of religious organisations sit on their boards of management. Also, as noted above, religious morals and culture are still dominant in Ireland. This underlining religious opinion is important to consider. As Ryan and McConkey (2000) discuss how politicians, community leaders, and family carers may adopt some of the associated religious morals associated with sexuality and even more so when it also relates to PWID. For example in Lafferty, McConkey, and Simpson (2012), they highlight how religious beliefs have been noted to play a significant role in parental objections to Sexual Education for PWID, owing to the conflicting views on matters such as contraception, homosexuality, and masturbation. They report on a parent interview on the subject of masturbation in the Sexual Education curriculum and recorded the following

“Masturbation is sinful! And against the Lord!”

Such insights detail the level of barriers that religion can pose for PWID when trying to access Sexual Education. They also demonstrate that these societal moral views of religion for PWID cannot be understated.

3.3.3 Criminal Law (Sexual Offences) Act 1993

In Ireland, Section 5 of the Criminal Law (Sexual Offences) Act 1993 outlined how it was an offence to have or attempt to have sexual intercourse or buggery with someone that was mentally impaired, unless they were married (NAMHI, 2003). For PWID, the law effectively meant that if two unmarried PWID were involved in a sexual relationship it “*may constitute a criminal offence*” (Gardiner & Braddon, 2009). This law was meant as a protective measure for those vulnerable. However, it instead left the regrettable situation that outside of marriage;

sexual relations between PWID might be viewed as breaking the law (Law Reform Commission, 2013). It created a position where if service providers supported PWID engaging in sexual acts; they and the PWID might be held criminally responsible (Drummond, 2006; Gardiner & Braddon, 2009). It should be stated that no such case was ever brought to the Irish courts on this matter (Johnson, Minogue, & Hopklins, 2014). However, the related ambiguity around the area allowed this view to be upheld; in both the caring structures and society (Kelly et al., 2009). ‘Inclusion Ireland’ (Irish Disability Advocacy Organisation) detailed the following

“We have.....seen the ‘chilling effect’ of the legislation with educators and advocates afraid to provide support to individuals with disabilities or provide education for fear of encouragement of law-breaking” (Inclusion Ireland, 2017a).

Researchers Grieve, McLaren, Lindsay, and Culling (2008) note similar effects and detailed as a result of this legalisation staff felt obliged to intervene when PWID became sexually active as they feared the risk of being prosecuted. With these noted difficulties the 1993 Criminal Act generated widespread criticism (Inclusion Ireland, 2017b). The 1993 Criminal Act created inconsistency among service providers. With some providers delivering support for PWID in their expression of relationships, while others enforced restrictive practices; which meant limited privacy, limited supports for staff and ultimately limited ability for the PWID to express their sexuality (Evans et al., 2009; Gardiner & Braddon, 2009; Healy et al., 2009; Kelly et al., 2009).

3.3.4 United Nations Convention on the Rights of Persons with Disabilities

In 2007, Ireland became a signatory to the United Nations Convention on the Rights of Persons with Disabilities – UNCRPD (United Nations, 2006). The article stressed the importance of the elimination of discrimination against persons with disabilities in all matters concerning marriage, relationships, and parenthood thus creating equal basis with others (Gardiner & Braddon, 2009). The UNCRPD represented a positive direction for PWID in Ireland; however, without the repeal of Section 5 of the Irish Criminal Act, 1993 ambiguity on the subject remained. Kelly et al. (2009) report that through their experiences they were aware of Irish service provider’s ‘Sexuality and Relationship’ policies that advocated for the international legislated disability rights (UNCRPD), however, they felt obliged to act in accordance with Irish laws. Service providers had a real fear that acting outside the parameters of Irish legislation would result in prosecution (Kelly et al., 2009). Although Ireland signed to this

convention in 2007, Ireland did not ratify it until April 2018. As a result, the 1993 Criminal Act was the main legal position, and it left service providers, staff and PWID in an uncertain position. If support was given, then prosecution could follow. This uncertainty regarding legalisation represents a primary role for the curtailing structures that were and continue to be provided by both service providers and their staff in Ireland. As a result, these legal implications are fundamental to the concept of sexuality in relation to PWID in Ireland.

3.3.5 Biopsychosocial Model and Special Needs Education (SEN)

As noted above, religious order's position as primary caregivers for PWID significantly diminished in the latter part of the 20th century. This was partly due to the dwindling numbers in religious orders; however, it was also due to the increased role of the new professionals providing this care in services. The advent of new professionals (Nursing, Social Care, Psychologists, Social Workers, Physiotherapists, Occupational Therapists, Speech and Language Therapists) brought a significant change in the model of care provided by services. Care shifted towards the biopsychosocial model. Through this model, support was delivered through the traditional biological means; but now, it was also framed through psychological and social contexts. These changes in both the model of care, and in turn, the staffing of Adult ID service providers had a significant effect on the culture and philosophy of service delivery. Services began to adapt and focus on reducing the social barriers that inhibited PWID. They did this by concentrating their efforts on changes in society rather than with the individual themselves (Thomas & Woods, 2003). Services under this model of care increasingly advocated for the equality and rights of the individual, by ensuring that PWID were to be included in society. They emphasised a person-centred approach, that supported PWID's ability to make their own life choices and be central in their own decision making (Purvis & Dick, 2005).

In tandem with these changes towards the biopsychosocial model of service delivery, educational access for all young PWID was also being recognised. The Education of Persons with Special Educational Needs - EPSEN ACT (2004) enabled all PWID in Ireland to access mainstream education. The ACT itself opened pathways for young PWID in terms of the overall numbers of young PWID accessing mainstream primary education (McConkey, Kelly, Craig, & Shevlin, 2016) but it also allowed young PWID to gain greater social inclusion through their presence in these mainstream classes (Drudy & Kinsella, 2009). This increased presence in society and the focus on young PWID's ability to attend mainstream education

challenged societies viewpoints on PWID's capabilities (Banks et.al., 2016). Overall, these changes towards the biopsychosocial model of care and equality of education access have significantly changed the landscape of societies viewing of PWID towards a focus on 'ability', rather than disability. These are important factors to consider in terms of the changing attitudes to intimate relationships and sexuality for PWID.

The impact of religion, legislation, care models and SEN cannot be underplayed in terms of ID service provision in Ireland. Their influence can still be seen directly in the day-to-day service delivery on the ground. The 1993 Criminal Law (Sexual Offences) Act required service providers to adopt practices and policies that represented these viewpoints, while religious influence brought their own restrictions in terms of Catholic teachings on sexuality. Meanwhile, changes in service model delivery, with new professionals and ideologies, coupled with SEN brought change in societies views of abilities and rights. As expressed above, service providers in Ireland do not exist in a vacuum. The impact of religion, legislation, care models and SEN has a significant bearing on their resulting policies and structures. The next section will consider other factors that impacted on these frameworks.

3.4 Service Provider Policy

Policy documents set the ethos and the standards for service providers; they give a framework for the basic requirements of the organisation while they also represent the method towards achieving excellence in an area (Cambridge, 2006). However, as Gilmore and Chambers (2010) state comprehensive policy around sexuality and intimate relationships for PWID appear to be rare in ID services.

3.4.1 Clarity of Policy Documents

Researchers report a lack of clarity on service provider's policy as key themes in their analysis of staff experiences in dealing with PWID sexuality (Grace, Greenhill, & Withers, 2017; Hollomotz, 2009). While Pebdani (2016) study of 71 staff members discussed how 46.5% of these staff reported that their service providers had no policy in relation to sexuality and intimate relationships. Under such systems when staff have no policy in place or when there is unclear instruction, Hollomotz (2009) noted that staff instead responded to issues using their own initiative based on their own personal and professional views. Other researchers (Ćwirynkalo et al., 2017; McConkey & Ryan, 2001; Rushbrooke et al., 2014; Ward, Trigler, & Pfeiffer, 2001) have described similar themes. With Carnaby and Cambridge (2002) noting that

staff would often use the approach of passing strategies by word of mouth, teaching each other, and following each other's example in dealing with these issues.

3.4.2 Policy Content

As well as policies having the potential to be vague and leaving staff to their own initiatives. Policies can also set ceilings in their protocols and be rigid in their application (Cambridge, 2006). This can result in stifling progressive initiatives in service delivery. Hamilton's research (2009) demonstrated that although staff reported liberal viewpoints on this issue, staff were subsequently curtailed by the overarching frameworks of the organisation and the legislation that could restrict sexual expression. Other researchers have reported similar difficulties with poor guidance and frameworks (Grace et al., 2017) and the limitations of an organisation's policy documents (Hollomotz, 2009). Research has noted that policy regulations appear to focus on the protection of PWID from abuse and sexual risk. However, they do not seem to account for the individual's ability and right to consent to sexual relationships (Lafferty et al., 2012). It is with this understanding that staff have expressed their frustration on the content of policy documents. Staff note that policy documents clearly define

'what they are not to do; however, they do not tell them what they can do' (Wilson et al., 2011).

Staff report that policy documents tend to focus on risk minimisation. For example, in Wilson et al. (2011) staff told of one young man with ID whose only opportunity to masturbate was while in the bath. However, due to risk, staff were never allowed to leave him unattended. Staff in this study detail that such restriction of sexual expression undermines the rights of the PWID; however, the policy and protocols in that service did not allow for deviation from this practice.

3.4.3 Policy Strength

Conversely, Abbott and Howarth (2007) highlight the importance of good policy and structures. They document a case where family members disputed a PWID's right to form a relationship. Staff, in this case, were able to reference the policy and detail the rights of the PWID ability to consent and engage in a relationship. As a result, staff were able to back the PWID in the face of parental opposition. Staff in this example reported feeling reduced fears and anxiety about the decision as they felt supported by the service and the policy structures in place. Indeed, researchers have recommended that the only way to address staff concerns and uncertainty is to provide adequate training and policy support, both of which need to be

practical in design so that they can have optimum performance in real life scenarios (Cambridge, 2006; Rushbrooke et al., 2014). Grace et al. (2017) outlines that both staff and PWID would be better served if these guidelines were made clear, practical and accessible in service provider's policy.

3.5 Welfare and Protection

The welfare and protection of PWID is to the forefront of the minds of all service providers and staff members. It is understood that PWID are vulnerable to risk and harm and it is important that policy reflects these known concerns (Brown & McCann, 2018). However, service providers still need to maintain a responsibility to deliver a service that achieves protection of PWID needs while also allowing for the autonomy of their human rights (Brown & McCann, 2018; Grace et al., 2017; Lafferty et al., 2012). This is a fine balance, owing to the vulnerability of PWID.

3.5.1 Vulnerability

PWID's level of ID and their associated perceived vulnerability is seen to influence the attitudes of staff towards their sexual expression (Ćwirynkalo et al., 2017; Gallagher, 2011; Grieve et al., 2008; Yool, Langdon, & Garner, 2003). Staff are seen to adhere to a more restrictive role towards sexual expression in supporting those with severe and profound IDs compared to those with mild and moderate IDs (Yool et al., 2003). Similarly, Evans et al. (2009) report that staff accepted and supported non-intimate relationships across the range of ID; however, for intimate relationships this acceptance reduced for those categorised as moderate to severe ID. This directly correlates to staff member's perception of these individuals perceived vulnerability and therefore the potential for risk. Staff are cognisant about the potential for sexual abuse within this population and as a result feel justified in protecting PWID, especially those with moderate to profound ID (Young, Gore, & McCarthy, 2012). As a result, there is a recognised difficult balancing act for staff in allowing PWID's sexual expression (Foley & Kelly, 2009). Staff are required to support PWID achieve their independence in sexual matters, while at the same time recognise their need for protection and safeguarding (Rushbrooke et al., 2014; Wilson et al., 2011). Maguire, Gleeson, and Holmes (2019) report that this is a difficult position where staff feel that supporting PWID with sexuality is a "*juggling act*". Such insights demonstrate the difficult position that staff face when supporting PWID in sexual matters. Research has demonstrated that when staff are faced with these difficult "*juggling*" responsibilities, staff can fall into the role of the paternalistic

carer. They can become the protector and sometimes lose sight of PWID's rights in relation to sexual expression (Tindall, 2015; Winges-Yanez, 2014). These are important factors to note. They emphasise the need for proper staffing supports in dealing with these issues so that staff can remain mindful of the PWID's rights.

3.6 Restrictions

In areas of sexual expression, PWID can be curtailed through the imposed restrictions of their service providers and staff (Isler, Beytut, Tas, & Conk, 2009).

3.6.1 Relationships and Sexual Encounters

Imposed restrictions for PWID on sexual matters can extend to all forms of relationship in the care services. Kelly et al. (2009) recorded the following communication regarding the subject of relationships with a PWID attending a service.

Interviewer: Do you have a girlfriend?

PWID: (. . .) I did kiss one of them on the lips at the time. Ya know, it was just nice And she was happy and I was happy so...

Interviewer: And (. . .) were you allowed do that (. . .)?

PWID: Ah, I was caught and then I got told off ...

It seems that the structures that are placed upon PWID in service providers can completely restrict any form of embrace with another person. This may have been as a result of the above content possibly leading to sexual acts. However, it clearly shows a restriction on PWID's need to form a sexual identity by developing and maintaining a proper relationship with others. In a qualitative study Grace et al. (2017) noted PWID's frustration at the restrictions imposed by the service providers and staff, with one person noting that she was

"allowed to hug once and that's it".

While other PWID reported that services and staff put pressure on them to end their existing relationship with another person in their service (Bernert, 2011). Similarly, in Healy et al. (2009) focus groups, they reported that PWID felt restricted in their ability to have romantic relationships. Interestingly, they did state that this was very much dependent on the services that PWID were attending. This discrete piece of information suggests the inconsistent rules and guidelines that PWID face in their expression of their sexuality in different service

providers. Other researchers, Bazzo, Nota, Soresi, Ferrari, and Minnes (2007) have similarly noted these inconsistencies between different services and their handling of these issues.

PWID in Healy et al. (2009) also discussed their viewpoint on the rules and restrictions that govern their service providers. One PWID participant reported that they are not considered

“I do really think that we don’t have any much of a life anyway”.

In another study, Abbott and Howarth (2007) detail a case where two adults with ID were attending a day service and they were discovered to be having sexual intercourse in a shed on the site. Staff reported that the service provider’s response to this, was to remove the shed. These above examples illustrate how forms of sexual identity for PWID are being denied through the structures of care. These restrictions are sometimes seen as the preferred options rather than facilitate and work with the associated risk (Yool et al., 2003).

3.6.2 Self-discovery and Masturbation

As outlined above, the lack of guidelines to deal with issues of sexual nature, leaves care staff in the position to either refuse, limit or give access to self-discovery based on their own personal and professional views (Healy et al., 2009). For example, staff report that they are often restricted in their approach to deal with PWID masturbating in service (Evans et al., 2009; Wilson et al., 2011). Restrictions are imposed where staff members cannot give PWID the opportunity to masturbate due to time restraints and the potential risk of leaving some of the adults unsupervised. In one such report, an example was given of a teenage boy who wore incontinence pads 24 hours a day. The boy was reported to constantly try to engage in masturbation when the pads were changed, however, he was never allowed to do so. To stimulate himself, he would lie on the ground fully clothed (otherwise in a wheelchair) and proceed to kick himself with his heel in the groin. Although the care staff recognised that he was trying to masturbate, the teenager was hardly ever given time to access his genitals (Wilson et al., 2011).

3.6.3 Resorting to Risky behaviour

Under the backdrop of these noted restrictive practices by service providers, it is noted that PWID can often resort to secrecy about their relationships (Kelly et al., 2009). As expressed the authorities view the imposed restrictions as necessary to protect those at greatest risk in society. However, such imposed restrictions can be counterproductive by forcing sexual activities into dangerous and risky situations (McCarthy, 1999). These risky behaviours can

develop from a place of fear. Kelly et al. (2009) reported how PWID had fears about having a relationship and told of their fear that they would be expelled from service. This can result in PWID being secretive about their relationship and their sexual expressions. One woman remarked of how she and her partner engaged in sexual intercourse in the bathroom of a filling station for fear of getting caught in the care services (Bernert, 2011). These forms of risky behaviour due to frustration at the restriction of their sexual identity have been strongly linked to the recent rise in both STD's and HIV for PWID (Noonan & Taylor Gomez, 2011). These are worrying developments and leave PWID further open to exploitation of sexual abuse and abusive relationships (Gallagher & Jennings, 2015).

3.7 Families

It is recognised that families play a significant role in the lives of PWID. For many PWID their family members remain their primary caregiver in their life. As a result, their views and attitudes on sexual matters can have a significant impact on them.

3.7.1 Guidance

PWID are recognised to be very reliant on their family supports for their knowledge and guidance in issues relating to sexuality (Evans et al., 2009). Indeed, PWID are noted to have limited social networks and as a result are seen to be more dependent on family members for information on sexual matters (Jahoda & Pownall, 2014). This can be an issue as Cuskelly and Bryde (2004) report that parents of PWID tend to have more conservative viewpoints on sexuality than paid staff. In addition, it is also noted that family members do not traditionally initiate conversations about sexuality with their relative (Abbott & Howarth, 2007). They are reported to be extremely cautious in talking about new avenues for their relative's sexual expression (Evans et al., 2009). Jahoda and Pownall (2014) suggest that families limit their relatives' access to information around sexual issues in order to keep them safe. Research demonstrates that there is an associated fear that discussion on this subject matter will lead to the encouragement of sexual behaviour and evoke sexual impulses (Abbott & Burns, 2007; Healy et al., 2009).

3.7.2 Fears

As noted for service providers and staff above; families face similar concerns for the protection and welfare of their relation. Research indicates that family tends to focus on the vulnerability of their family member and therefore on their potential to be abused (Swango-Wilson, 2009).

In addition, family members also cite their fears around their relative becoming pregnant. Research details that family members fear they will become the child's primary caregiver due to their relative being unable to care for the child because of their cognitive and adaptive deficits. For these reasons, families have been mostly found to encourage more friendships rather than intimate relationships for their relative (Löfgren-Mårtenson, 2004).

3.7.3 Family and the Service Providers

This strong family member need to overprotect and the tendency to control their relative's sexuality in services has been observed by staff (Ćwirynkalo et al., 2017). As a result, service providers and staff have indicated that they can fear dealing with PWID's family members when they are required to support PWID's sexuality. In these circumstances, service providers have been seen to respect family concerns rather than create ongoing conflict. An Irish Adult ID service provider's CEO captured this difficulty (O'Sullivan, 2014)

“fighting the demands of the parents versus the demands of the individuals.... you've got individuals wanting to have relationships with people and parents against it...if parents feel that they are being over-ruled... (this can leave organisations in) ...an uncomfortable place”.

This difficulty often leaves the sexual expression of PWID being suppressed. Services are seen to discourage relationships in order to avoid potential lawsuits and difficulties with PWID's family members (Valenti-Hein & Choinski, 2016).

3.8 Staff Member's Values and Attitudes

Many PWID rely on staff support for many aspects of their life and as a result, staff values, beliefs, and attitudes can greatly inform PWID day-to-day living (Abbott & Howarth, 2007; Meaney-Tavares & Gavidia-Payne, 2012). As Gallagher (2011) states PWID are seen to have fewer avenues for learning about sexuality from traditional means and as such, PWID are more reliant on staff support on these issues. PWID might seek education and guidance, and support for expressing their sexuality (Evans et al., 2009). As a result, the staff member's viewpoints and their resulting actions on these issues can either suppress or support PWID's expression of sexuality (Abbott & Burns, 2007; Gilmore & Chambers, 2010). PWID are therefore extremely vulnerable to the attitudes and personal beliefs of their care staff.

3.8.1 Staff Demographics

Previous research indicates that staff tends to hold positive views on the sexual rights of PWID. Certain staff demographics have been reported to be linked with liberal and conservative

viewpoints towards sexuality for PWID. However, research on these demographic differences for staff attitudes has been found to be contradictory. For example, some research demonstrates that younger staff tend to have more liberal views on sexuality in service providers. Cuskelly and Bryde (2004) cite that demographics such as being younger increase the likelihood to be liberal in this area. Similarly, Aunos and Feldman (2002) report that older staff members had the least liberal attitudes. While in an Irish study, Evans et al. (2009) noted similar trends with older staff and suggested that this older generation may well be influenced by their traditional Catholic teachings and practices from their upbringing. However, Gilmore and Chambers (2010) noted there were no differences in attitudes based on the age of participants. This same study cited there were also no differences in attitudes with those that had higher educational levels. Whereas other research has associated higher educational attainment and being in professional or managerial positions as increasing the likelihood to be liberal in this area (Cuskelly & Bryde, 2004; Saxe & Flanagan, 2013).

3.8.2 Religion

As previously noted, religious affiliation has been reported to influence staff attitudes and beliefs towards issues of relationships and sexuality for PWID. Research indicates that staff's pre-existing values and religious beliefs have been noted to restrict staff member's ability to have conversations on this issue (Allen & Seery, 2007). Several studies have reported that those staff with strong religious beliefs held more conservative viewpoints than those that did not hold such beliefs (Chou, Lu, & Lin, 2018; Meaney-Tavares & Gavidia-Payne, 2012; Saxe & Flanagan, 2013). It has been noted that staff member's strong religious identity has been seen to be linked to the associated perception of the "eternalised child". This leads to the conservative viewpoint that PWID need protection from all sexual matters (Lafferty et al., 2012; Ryan & McConkey, 2000).

3.8.3 Homosexuality

Discussed above are some of the points where there are substantial restrictions in regard to a heterosexual relationship, however, the further resulting stigma if the individual wishes to pursue a homosexual relationship can be far more daunting (Abbott & Burns, 2007; McCann, Lee, & Brown, 2016; Noonan & Taylor Gomez, 2011). Preconceived prejudices or opinions that staff members might have on the subject can directly impinge on the PWID's sexual rights (Abbott & Burns, 2007). Clarke and Finnegan (2005) addressed this issue and found that 76% of staff would support a heterosexual relationship; however, only 41% of staff stated they

would support a homosexual relationship. Such a disparity might well lay with the staff member's moral interpretations of homosexuality. The effects of which can have devastating effects on PWID. Indeed, many openly homosexual PWID reported their level of frustration when first trying to communicate their feelings (McCann et al., 2016). They spoke about their want to talk to somebody, but the resources were not provided and as a result, they slipped into further depression and isolation (Abbott & Burns, 2007; Noonan & Taylor Gomez, 2011). As a result, PWID have tried to commit suicide, with one person in (Noonan & Taylor Gomez, 2011) remarking

'Why am I getting punished, why am I having the life of a child instead of an adult'.

Grace et al. (2017) reported that some staff members express their homophobic beliefs towards PWID, with one respondent stating that a staff member remarked to them that

"God made Adam and Eve, not Adam and Steve".

This area of sexuality is particularly distressing, in that PWID are not only restricted by their disability, but they are also restricted by societies view of homosexuality.

As noted above, the personal factors in relation to staff attitudes on this matter are still not clearly understood (Pebdani, 2016). However, it remains important to try and understand these different values and beliefs that staff have in relation to PWID's expression of sexuality as staff report that it is difficult to ignore personal attitudes and beliefs. For example, in Maguire et al. (2019) they report that a staff recorded their views on supporting a PWID access internet pornography. The staff member responded that they would feel conflicted, as they themselves

"find pornography bad".

Such examples show how personal beliefs and moral standards can be seen to directly impinge on PWID's right to pursue sexual expression.

3.9 Staff Experiences

Staff working in Adult ID service providers report different experiences supporting PWID in their expression of sexuality. Therefore, the staff member's perception of their role and their ability to support PWID's expression of sexuality is important to note.

3.9.1 Staff Experiences

Staff have been documented to hold different perceptions on the sexuality of PWID. It is noted above that these are influenced by different demographics and cultural influences. For the most

part, staff have been documented to have positive perceptions on sexuality and relationships for PWID. In Yool et al. (2003) study they document how staff see sexuality as part of being human, and as a result that no one should be denied their opportunity to express it. Similarly, Ćwirynkalo et al. (2017) qualitative research noted that staff very much focused on the capability of PWID to engage in intimate relationships. The staff in their study reported on PWID's ability to love, to be responsible and their ability to control their sexual behaviour. In contrast, other research notes that staff perceptions of PWID's sexuality can tend to focus on negatively associated behaviours of inappropriate touching, excessive masturbation, and abusive acts. Research cites that this perception is formatted by what staff experience at meetings and behaviour management settings (Lafferty et al., 2012). Staff in services tend to see PWID's sexuality expressed and then discussed in reactionary behaviour support context rather than positive relationship goals (Abbott & Burns, 2007).

3.9.2 Staff talking about Sex

As noted, PWID are particularly reliant on staff members to provide information and guidance on Sexual Education to them (Evans et al., 2009). However, some staff perceive sexuality as an extremely private matter where they believe it should not be discussed as part of their employment (Wilson et al., 2011). It is important to recognise that having conversations about sexuality and relationships can be difficult. Staff can feel uncomfortable in broaching the subject (Rushbrooke et al., 2014). This can stem from numerous reasons including fear and accountability, embarrassment, pre-existing values and religious beliefs and feelings of intruding on PWID's privacy. Staff report their fear is enhanced by their feelings on their lack of confidence in dealing with sexuality issues when they arise. It is noted that this fear and anxiety is perhaps one of the reasons why staff find it difficult to engage with PWID on issues of sexuality (Rushbrooke et al., 2014).

Staff report feeling embarrassed about having conversations about relationships and sexuality. Lockheart, Guerin, Shanahan, and Coyle (2009) qualitative study reported how some staff had great difficulty in discussing the subject. They describe how good staff working in challenging behaviour settings could not read the word "*penis*" during staff meetings. These staff noted that talking about sex made them feel "*uncomfortable*" and they felt it was outside their "*comfort zone*". This fear to discuss these matters has also been noted by the PWID they support. Healy et al. (2009) reported that PWID also perceived that staff were "*afraid to talk about it*". Staff note this uncertainty is based on the fear of accountability, their own confidence

coupled with feeling embarrassed that they would be intrusive on what they consider a private matter for PWID. As a result, the staff would generally wait for PWID to engage in conversation with staff on this topic.

“if they asked anything then I would try as best as I can, I probably wouldn’t broach the subject” Pownall and Jahoda (2011)

These areas can be difficult subject matters but, as noted by McCabe (1999) a lack of discussion around these issues with PWID leads to insufficient knowledge on sexual issues and impedes PWID’s right and sexual expression.

3.10 Staff Training

Research indicates that staff do not receive adequate training regarding relationships and sexuality for PWID, with staff often reporting feeling unsupported by their service providers. (Abbott & Howarth, 2007; Carnaby & Cambridge, 2002; Gardiner & Braddon, 2009; Ward et al., 2001).

3.10.1 Training Needs

Wilson et al. (2011) highlight that staff are working admirably under the backdrop of broad organisational policy but are offered little in the way of assistance on day-to-day ethical issues; for example, dealing with hugs, touching or masturbation during personal care. Staff regularly face these issues, and they recognise the importance of sexuality training for themselves in dealing with such issues (Bernert, 2011; Kelly et al., 2009; Ward et al., 2001). In McConkey and Ryan (2001) study, they report that just 25% of staff received sexuality training, while 18.3% of staff received sexuality training in Pebdani (2016) study. Similarly, in Evans et al. (2009) study they report that just 12% of staff had received training in this area. However, in the same study, 95% of staff recorded a want to access such training (Evans et al., 2009). In Lafferty et al. (2012) qualitative study they reported similarly low levels of training among staff members and for some their training was ten years previous. They reported that when training was run in services, it was limited. They noted that even when staff expressed interest not everyone that applied could access it and instead places went to selected members of staff. Rushbrooke et al. (2014) report similar findings on the lack of training.

3.10.2 Benefits of Training

It is noted that training and support around sexuality reduce staff anxiety and fears about working with PWID on these issues (Rushbrooke et al., 2014). Gardiner and Braddon (2009)

document that staff training in this area generates numerous advantages. It reduces staff anxiety, it increases PWID Sexual Education, and it reduces PWID's family members concerns around sexual issues. Rushbrooke et al. (2014) assert that training normalises sexuality and relationships for PWID. It gives staff, the support and information they require to, in turn offer PWID the same level of support in their development of their sexuality. The absence of staff training in this area leaves staff feeling vulnerable and ill-equipped to deal with issues that they might face (Lafferty et al., 2012). Meaney-Tavares and Gavidia-Payne (2012) also reported on the significance of training in staff attitudes. They found that training increased staff feelings of competency and understanding while simultaneously decreasing their fears around dealing with sexualised behaviours (Meaney-Tavares & Gavidia-Payne, 2012). Pebdani (2016) report similar results and state that training in this area can also have a positive effect on staff attitudes towards PWID's sexuality.

Training for staff in sexuality and intimate relationships is fundamental to the promotion of PWID's rights in this area. Without this staff do not have the remit to offer correct advice or give appropriate guidance (Foley & Kelly, 2009). Training improves dialogue; it shifts negative perceptions and decreases the taboo nature of the subject matter. Positive staff interactions with PWID around sexuality have the potential to lead to normalised life experiences for PWID (Gilmore & Chambers, 2010). Whereas, Cuskelly and Bryde (2004) report negative interactions and inconsistent messages from staff in relation to sexuality can lead to confusion about their sexuality and in turn develop negative feelings.

3.11 PWID Sexual Education

Sexual Education for PWID is seen as a fundamental aspect of their sexual development and identity. Good Sexual Education can help PWID recognise inappropriate sexual advances and the potential for abuse (Isler et al., 2009; Noonan & Taylor Gomez, 2011), it can also help with safe sex practices and generally inform positive viewpoints about sexuality (Schaafsma et al., 2015). However, for the majority of PWID, their Sexual Education often results in limited knowledge that is partial or incomplete (Allen & Seery, 2007; Sinclair, Unruh, Lindstrom, & Scanlon, 2015).

3.11.1 Method of delivery

Research notes that Sexual Education is often delivered in group settings as broad curriculums (Dukes & McGuire, 2009) and it has been traditionally characterised as controlling impulses and providing limited information that is theoretical but has very little practical application

(Aunos & Feldman, 2002; Gil-Llario et al., 2018). It is also noted that it is usually a reactionary process to problem behaviours rather than one of support where it teaches about the inappropriateness of touch of others, in areas such as harassment and abuse (Abbott & Burns, 2007; Lafferty et al., 2012; McCabe, 1999). Although these issues are critical in the construction of PWID's education, especially considering their vulnerable state. The failure to address the full aspect of sexuality leaves PWID misinformed (Wilson et al., 2011). As a result, their impending relationships and possible sexual activity may also be misinformed; therefore, restricting the expression of their sexual identity.

3.11.2 Knowledge

From this limited resource, PWID have been shown to have a low knowledge base around sexual matters; such as masturbation, sexual health, homosexuality and pregnancy (Healy et al., 2009; Kelly et al., 2009; McCarthy, 1999; Medina-Rico, López-Ramos, & Quiñonez, 2018). This lack of information and knowledge on sexual issues has been recognised to make PWID more vulnerable to potential abuses (McDaniels & Fleming, 2016). In Kelly et al. (2009) focus group interviews with PWID, they documented that the researchers received many requests to provide missing sexual information to the PWID. Research states that not equipping PWID with information about their bodies at the appropriate age can leave them confused and afraid (Schaafsma et al., 2015). Debate remains over the appropriate time that such an education should take place. This is in large part due to the discrepancy between PWID's physical maturation and their cognitive development (McDaniels & Fleming, 2016). However, reported instances where PWID apologise for 'wetting the bed' due to nocturnal emissions or the expression of confusion and fright from having erections are far from ideal (Valenti-Hein & Choinski, 2016).

3.11.3 Sources of Information

In addition to the poor educational resources, Pownall and Jahoda (2011) highlight that many young PWID feel uncomfortable discussing issues relating to sexuality with staff and instead seek advice from their peers. Due to the limited knowledge on offer, this often leads to inaccurate information for those concerned. Kelly et al. (2009) highlight that when PWID are not taught formal Sexual Education they tend to pick up this information from other sources. They note that PWID can acquire their information from different media sources like TV programmes, film, and magazines. They report that this information can be ill-informed and

lead to misunderstandings. Kelly et al. (2009) had the following conversation with a woman with an ID on the topic of affairs

Interviewer: What are affairs?

PWID: When you're in bed. Beside them (....) They put their hands around ya (...) or give you a kiss or something (....) And someone walks in and found ya in bed. Someone else comes in (....)

And then war breaks out.

The woman appears to have identified 'affairs' with the dramatization associated with TV soaps. Similarly, in Healy et al. (2009) they report how a man with ID in their study, knew that a woman got pregnant. However, when questioned how this happens, he replied that

"you eat too much".

These forms of miscommunication identify only an aspect of where poorly resourced education plays a role in PWID's view of their sexuality.

3.12 Criminal Law (Sexual Offences) Act 2017

In March 2017, the 1993 Criminal Law (Sexual Offences) Act was repealed. The new Criminal Law (Sexual Offences) Act 2017 now focuses on the person's "capacity" to have sexual contact and less on the person's disability (Inclusion Ireland, 2017b). It presumes that a person has the capacity to act in their own accord. If concerns are raised it is incumbent on service provider and/or carers to ascertain that the person does not have the capacity to consent to sexual contact. In addition, the reference to marriage for sexual relationships has been removed. This change in legislation signals a shift towards equality for PWID in relation to sexual matters. It has been largely welcomed by ID advocacy groups as it recognises the right for relationships and sexual expression but still offers protection to those most vulnerable.

3.13 Current Study

Outlined above are the pertinent factors for relationships and sexuality for PWID. As demonstrated legislation, family, religion, service provider policy and staff attitudes all exert a significant influence on this subject matter. PWID can have their sexual identity be suppressed whether consciously, through to the limitations put forward by the relevant authorities (judicial acts, structures of care) or alternatively, unconsciously, through lack of knowledge and understanding for their needs (Grace et al., 2017). This suppression needs to be understood before it can change. Service providers and staff have a collective responsibility to

acknowledge that PWID are not unlike peers without a disability, in that, they too have the same sexual needs and desires (Yool et al., 2003).

3.13.1 Need for Current Study

There is a dearth of disseminated literature on ‘Relationship and Sexuality Policy’ structures that govern Adult ID service providers, with previous research documenting minimal reference to these policies in their literature reviews (Azzopardi-Lane, 2017; Foley & Kelly, 2009; Hollomotz, 2009). As such, as far as the researcher is aware, no published study has been undertaken directly analysing service provider’s ‘Relationship and Sexuality’ policy documents. Interestingly, Wilson et al. (2011) have cited that although much of the previous research in this area has centred on staff attitudes in relation to PWID and sexuality. They maintain that the overarching socio-structural limitations of policies and organisation standards can have a much more significant impact on the expression of sexuality (Wilson et al., 2011). For these same reasons, the researcher contends that this project is extremely worthwhile.

In addition, the last series of Irish studies on this subject matter were published in 2009 (Evans et al., 2009; Gardiner & Braddon, 2009; Healy et al., 2009; Kelly et al., 2009). Much has changed in Ireland in those intervening years; socially, culturally and now specific to this matter, legally. With the repeal of the 1993 legislation in 2017, it is necessary to examine if service providers have noted these changes and adapted their policy accordingly. It is also worthy to consider if staff knowledge of the changed legislation has influenced their attitudes and beliefs in this area. As a result, it is vital to evaluate staff attitudes and beliefs towards this issue and their willingness to support or restrict such activities. Research is also required to understand the potential barriers and concerns that staff are currently experiencing.

Therefore, the primary research question for this study is:

“To explore the attitudes and views of Adult ID Service Providers (Policy documents) and their staff members in their work with PWID in the area of intimate relationships and sexuality”.

This research aims to provide a current audit of where service providers and staff are in facilitating intimate relationships and sexual expression for adults with ID in Ireland. As different service providers can offer different viewpoints on these issues (Healy et al., 2009), it was felt that a national study involving various service providers would give a good representative sample.

For this achieved, three main research questions will be investigated. 1). service provider's policy documents will be critically analysed to explore their delivery on relationships and sexuality for people with ID. This exploration will consider their themes of support and/or restrictions in the area, and whether these policies reflect the changes in the current legislation. It will detail the meanings delivered from their policy content; through language, narrative, and structures. This exploration will provide a comprehensive review of current service policy. 2). the impact of staff attitudes will be investigated. It is predicted that staff of younger age, higher education, non-religious affiliation, those that received training and were aware of policy in the area, will show more liberal attitudes in issues of sexuality for PWID. 3). this research will also explore current staff sentiment; detailing their views and beliefs, while also capturing their lived experiences of the potential barriers and the concerns they are currently experiencing while working with PWID in the area of sexuality and intimate relationships. By reviewing these three research questions, it will be possible to gain a perspective on the structures of Adult ID service provision in Ireland and detail the areas that need to be addressed in the future.

Chapter 4. Methodology

4.1 Chapter Introduction

This chapter will outline a description of the methodology used in this current study. It will begin with the researcher's rationale for the mixed methods approach used. It will continue by discussing the sampling methods used, regarding both the service providers and staff participants recruited. The chapter will then detail the source materials used. It will discuss the issues with the ethical processes required for the study, and it will explain the necessary changes that were made. The concluding section will give a comprehensive review of the procedures employed during data collection and outline the data analysis techniques used.

4.2 Rationale for Mixed Methodology

Quantitative and Qualitative research methods are supported under two distinct paradigms. Positivism, where realities are external to the researcher and therefore are required to be studied through rigorous scientific methods; and constructivism, where the meaning is deemed not external and it is instead derived from the subject's interactions with the world (Gray, 2014). Based on these distinct philosophical approaches, researchers have traditionally either singularly adopted qualitative or quantitative research methods (Kelle, 2006). However, in recent years there has been a movement towards a combination of these methodologies (Johnson, Onwuegbuzie, & Turner, 2007). Mixed Methodology represents a dovetailing of both the statistical trends from quantitative research with the detailed personal experiences from qualitative research (Kelle, 2006). The central premise of this method is that there is a collective strength when combining both of these approaches (Creswell, 2009). It is stated that it can provide a more thorough understanding of the phenomenon than either of the methods alone (Creswell & Plano Clark, 2007).

Quantitative research methods involve the quantifying of data, by assessing cause and effect relationships between variables through a process of statistical testing. It generates hard data; that can determine counts, ratings and classifications (Gravetter & Wallnau, 2009). However, critics note that it can lose depth of individual meaning because it reduces experiences to numerical values (Pietkiewicz & Smith, 2014). Whereas, in contrast with qualitative methods the researcher has the opportunity to acquire rich or 'thick' data (Geertz, 1973) that can give more in-depth analysis of the subject matter. Qualitative research enables the researcher to 'make sense of, or interpret phenomena' and explore peoples' individual

experiences (Kasinath, 2013). Proponents highlight that this methodology can go beyond the collecting of facts, towards instead providing the actual scientific explanations of facts (Flick, 2009).

The primary aim of this study was to explore the current attitudes and views of Adult ID Service Providers and their staff members in the area of intimate relationships and sexuality. For this to be achieved it was felt that a national study of various service providers would give a good representation. From the above, it was deemed that a mixed methodological approach would best suit this research aim. Qualitative methods would be used to review the service provider's 'Sexuality and Relationship' policy documents. This would allow for in-depth analysis of the service provider's current construction of PWID's intimate relationships and sexuality within their service. In addition, qualitative methods would also be used to review the open-ended answers provided by staff in relation to their attitudes and experiences of their current work in services. While quantitative methods would be utilised to further examine staff members 'attitudes to sexuality'. By identifying how certain demographic features are associated with their attitudes towards PWID's sexual rights, parenting, non-reproductive sexual behaviour and self-control.

4.3 Thematic Analysis

A range of qualitative approaches were considered for this study. Discourse analysis was considered. However, its focus on the regulatory and constructionist function of language meant that it perhaps would diminish other latent patterns in the data (Silverman, 2013). This method was rejected. Content analysis was considered. Content analysis is described by Flick (2009) as a classical procedure for analysing textual material. This process involves the researcher creating a coding system that is applied in discrete categories to the subject matter in a consistent manner. However, given that these categories are subsequently converted to quantitative data, which critics have cited can lead to a reduction in the richness and quality of the qualitative data. This method was also rejected.

The use of thematic analysis was considered. It presents an adaptable approach to qualitative inquiry that is not bound to established theoretical frameworks. Therefore allowing the researcher to assume constructionist, essentialist/realist, or contextualist approaches to their research query (Braun, Clarke, & Terry, 2014). Thematic analysis as a method provides a way to systematically identify, organise and offer meaning (themes) across a data set. It allows the researcher to see and interpret these meanings and experiences so that the content can be

summarised (Braun & Clarke, 2012). Thematic analysis allows the researcher to report on the semantic meanings in the data. However, it also allows the researcher to interpret the latent meanings and assumptions by ‘drilling down’ to try and understand why the text has been structured in such a way (Braun & Clarke, 2006). In addition, previous studies have used thematic analysis to analyse policy documents (Robinson, Gott, Gardiner, & Ingleton, 2016). For all these above reasons, the use of thematic analysis was deemed the most appropriate.

4.4 Sampling

4.4.1 Method of sampling

A list of registered Adult Intellectual Disability services in Ireland was acquired by telephoning Health Information and Quality Authority (HIQA) services. From this list, eight Irish service providers were selected to be contacted. These eight services were selected based on their geography/location and the size of their service. These services were contacted by telephone and through email correspondence, either directly through their CEO or through their Psychology departments. Five from the eight service providers corresponded and agreed for ethical approval to be sought from their services to complete the study.

4.4.2 Sample Size

The five Irish Adult ID service providers provided a broad geographical coverage, ensuring a representative sample throughout Ireland (Clare, Cork, Dublin, Galway, Kerry, Limerick, Mayo, Offaly, Roscommon and Tipperary). Each service provider in the study reported between 100 - 500 employees. Based on attrition estimated from a methodological perspective, it was estimated that the sample size should range from 50 to 200 staff members from the five service providers. A minimum of 45 was required for a priori large effect power criteria to be met.

4.5 Participants

4.5.1 Service Providers

The five service providers that agreed to participate were asked to provide explicit consent to analyse their ‘Relationship and Sexuality’ policy documents.

4.5.2 Staff

Participants included all employees over 18 years, that worked for these five service providers. It was stipulated that these employees needed to be actively working during the time of data

collection to best represent their views on this matter. There were no other exclusion criteria. All employees were included; management, Allied Health professionals, front-line staff, administration. Given the nature of the study, it was not possible to estimate the total number of employees contacted, as administrators disseminated the surveys directly to staff via email and recruited via a recruitment poster (see appendix A). No financial remuneration or any other form of reward was offered to participants.

4.5.3 Characteristics

There were 86 staff participants in total, 16 males and 70 females. Staff had spent between 1 year and 40 years working in Adult ID services; $M = 13.4$ years ($SD 10.1$). Further details on the participants are presented in Table 1. It is noted that staff support a range of different people in Adult ID services; as such there is a crossover of who they support. These are detailed by gender and level of ID in Table 2.

Table 1. Frequencies and percentages of respondents in each demographic category (n=86)

Demographic Factor	Category	Frequency	Percentage
Gender	Female	70	81.4%
	Male	16	18.6%
Age	18 - 25 years	10	11.6%
	26 - 35 years	22	25.6%
	36 – 45 years	25	29.1%
	46 – 55 years	20	23.3%
	56 – 65+ years	9	10.5%
Highest Education	Secondary School	4	4.7%
	Third Level Cert/Dip (Level 5/6	21	24.4%
	Undergraduate (level 7/8)	32	37.2%
	Postgraduate (Level 9/10)	29	33.7%
Staff Occupation	Social Care Worker	21	24.4%
	Health Care Assistant	17	19.8%
	Instructor	10	11.6%
	Management	11	12.8%
	Allied Health Professional	14	16.3%
	Nurse	11	12.8%
	Other/Admin	2	2.3%
Religion	Roman Catholic	65	75.6%
	Church of Ireland	3	3.5%
	Presbyterian	1	1.2%
	Other (not named)	3	3.5%
	No Religion	14	16.3%
Practice Religion	Yes	25	29.1%
	No	34	39.5%
	Sometimes	27	31.4%

Table 2. Demographics of who staff support (n=86)

Demographic Factor	Category	Frequency	Percentage
Supporting Gender	Female	76	88.4%
	Male	69	80.2%
Supporting Level of ID	Mild	40	46.5%
	Moderate	69	80.2%
	Severe	46	53.5%
	Profound	23	26.7%

4.6 Materials

4.6.1 Policy Documents

Five Service Providers took part in the study. Table 3 below represents these services 'Relationship and Sexuality' policy documents that were used for analysis in this study.

Table 3. Service Provider's "Relationship and Sexuality" Policy Documents

Service	Published Year	Length	Review Date
One	Not in service	9 pages	N/A
Two	2008	13 pages	3 years
Three	2011	11 pages	Annual review
Four	2008	13 pages	Due in 2010
Five	2014	13 pages	3 years or sooner if legislation changes

*All the service policy documents included in this analysis were the policy documents that were available to their staff members as of January 2019.

Firstly, it is worth noting that four of five service providers had active policies. Service provider One had no policy in relation to 'Relationship and Sexuality' in operation. This service had been founded in 1966. The policy submitted for this research was under review for circulation with staff in 2019. Secondly, the dates of these documents also need to be observed. Two of the documents were originally drafted over ten years ago, with their stated review dates to be between eight and nine years ago. Also, only one of the five policies had a reference list. References used included two policy documents from other organisations in the early 2000s, and the rest was literature from the mid-to-early 1990s. Thirdly, in two of the documents, their table of contents page numbers did not match with the corresponding section in the document, with one document having two pages less than indicated with no references included as described in the contents. This same document also had the same author as the person reported as reviewing the document. Fourthly, it is worth noting that only one document had legal representation for one of its co-authors. Finally, one policy document provided a feedback sheet in the appendix so that staff could make comment on the contents.

4.6.2 Survey

This study consisted of a 15-minute online survey questionnaire (see appendix D). The survey consisted of demographic questions that were based on previous research findings. In addition,

yes/no questions with options to comment about PWID and sexuality were included. These were based on the researcher's review of the literature. Open-ended qualitative questions were also included around staff member's opinions on potential barriers and future recommendations for this area.

The Attitudes to Sexuality Questionnaire - Individuals with an Intellectual Disability (ASQ-ID; (Cuskelly & Bryde, 2004) had high test-retest reliability ($r = 0.91$) and good internal consistency (Cronbach's $\alpha > 0.90$). A factor analysis of this questionnaire reveals four subscales; Sexual Rights (13 items, for example, 'Sexual intercourse should be permitted between consenting adults with ID'); Parenting (7 items, example 'Care staff and parents should discourage people with ID from having children'); Non-Reproductive Sexual Behaviour (5 items, for example 'Masturbation in private for people with ID is an acceptable form of sexual expression') and Self-Control (3 items, for example 'People with ID are more easily stimulated sexually than people without ID'). Questions were answered on a six-point Likert scale, ranging from strongly disagree to strongly agree. Higher scores indicated more liberal attitudes, or more positive and accepting attitudes, towards the sexuality of PWID. Seventeen items in the questionnaire were reverse coded.

In 2007, Cuskelly and Gilmore revised the original Attitudes to Sexuality Questionnaire (Cuskelly & Bryde, 2004), by separating the questionnaire into two sections, one female with ID and one male with ID. This version also made some changes by adding three additional questions on stereotypical views of sexuality. These questions (below) were intended to capture the idea that PWID have little interest in sex.

Q 5. People with ID have less interest in sex than adults without an Intellectual Disability (R)

Q 13. Adults with an Intellectual Disability typically have fewer sexual interests than adults without an Intellectual Disability (R)

Q 34. adults with an Intellectual Disability have stronger sexual feelings than other women (R)

In addition, Cuskelly and Gilmore removed another question about whether masturbation was morally wrong, as Cuskelly and Bryde (2004) found that it did not assist with their interpretation of the results. As a result of these changes the researcher decided to use the new questions of the 2007 version, however, they decided to revert to the single-gender base of the original 2004 survey due to gender not being overtly relevant to their research question (Appendix E). The possibility of participant fatigue in completing a more extended survey played a considerable role in coming to this conclusion. In addition, other published

researchers, for example, Pebdani (2016) used a single gender version of the Cuskelly and Gilmore (2007) questionnaire in their study.

4.7 Ethical Process

A Research Proposal was presented to the UL Psychology Department. Written permission for the study and ethical approval was granted through UL ethics committee (Appendix F). Service provider One who did not have a local ethics committee accepted UL ethics approval with additional documentation. However, the four other service providers required that their local ethical committee review the project. These are represented in Table 4. Ethical concerns were continually monitored and reflected throughout the research process.

Table 4. Details of Service Providers Ethical Applications

Service Provider Two	Service Provider Three	Service Provider Four	Service Provider Five
<p>Concerns: An ethics review meeting was called with their local ethics board to expediate the ethics process. Their ethics board raised practical concerns around the use of an online survey as the organisation noted that most staff did not have access to the internet.</p>	<p>Concerns: Requested that two of the survey questions would be removed for ethical approval to be granted.</p> <p><i>Q1: In your experience, do service users have access to sexual materials? And if so, what items are available?</i></p> <p><i>Q2: What areas around relationships and sexuality with the people that you support cause you concern?</i></p> <p>The researcher sought clarity around the suggested removal of these questions. The service only provided reasoning for Question 2. No explanation was given for the removal of Question 1.</p> <p>They were “concerned about the duty of care of participants and should abuse or</p>	<p>Concerns: This ethics board initially replied with a complete refusal. No explanation was offered around their initial refusal. However, the researcher continued to request information on their refusal, in order to amend and reapply to their ethics board.</p> <p>They reported concerns over the inclusion of public participants. They noted their concern that public opinion on this topic could be seen to “sensationalise” this subject matter.</p> <p>They also noted that benefits to the service and the absence of service user input as their primary concerns about the study.</p>	<p>Concerns: The ethics board gave conditional ethics approval to the study on the basis that personal demographic information would be reduced due to GDPR guidance.</p>

	<i>behaviours that would be seen as a client having been placed in a position where misconduct occurred that there would be no avenue to explore same”.</i>		
Amendments: The circulation of hardcopy posters was suggested to be used in the Service to help staff accessing the questionnaire. However, the survey would remain online due to practical difficulties in supplying and collecting paper copies.	Amendments: The researcher reluctantly removed both questions for the entire study to continue.	Amendments: Considerable correspondence between the researcher and the ethics board took place over many weeks and months with ethical approval eventually being granted when the researcher withdrew the public section of the study.	Amendments: it was agreed to remove details of the service providers and service location on the demographics. However, following these amendments, there was a significant delay in granting full ethical approval. As a result, the questionnaire was circulated for a much shorter time in their service.
Outcome: Ethical Approval Granted	Outcome: Ethical Approval Granted	Outcome: Ethical Approval Granted	Outcome: Ethical Approval Granted

4.8 Survey Amendments

As noted above in Table 4, the ethical applications to these individual service providers' ethics boards resulted in necessary amendments to the study. Most significant was the removal of the 'general public' from the study. This service was very definite in its position to remove this section of the study. Considerable conversations were had with the service, via telephone, email and in person over many months to try and seek resolution; however, in the end, the researcher reluctantly removed this section. These ethical processes will be considered further in the discussion chapter.

4.9 Procedure

4.9.1 Inclusion and Exclusion Criteria

Participants were sourced through the five service providers. An email was circulated to staff members by a local service provider administrator. In line with current data protection regulations, the researchers did not have nor require access to these emails. Staff were presented with the relevant information, consent and a link to the anonymous online survey. Survey data was collected via an online survey Questback (<https://www.questback.com>) an online survey platform. All data recorded was anonymous. After 2-3 weeks, staff were sent another email by the administrator reminding them to complete the survey should they not have done so at that point. In addition, a recruitment poster was generated to be posted around services, outlining the study and providing a link to the questionnaire (appendix A). Surveys for this study were circulated from September 2018 through to December 2018 and participants were informed that the survey would close in January 2019.

4.9.2 Confidentiality and Anonymity

Organisations and research participants were informed that they were under no obligation to participate in the study. They were also informed that their anonymity would be guaranteed and that no individual results would be reported in any publications. Only aggregated data relating to the whole group would be reported and discussed. Each participant accessed the survey through the online survey website. This included an invitation letter, an information sheet (Appendix C) and informed consent (Appendix B) to be selected through the website. To ensure that respondents would complete the surveys in an open manner, no clear identifying information was gathered through the process.

4.9.3 Survey Pilot-study

A pilot study was carried out with health care professionals familiar with the area. Their feedback was used to correct typographical errors in the wording of the questions and instructions.

4.9.4. Data-handling.

Anonymised data was downloaded from the Questback online survey website into a password protected Excel file for Windows. The data was error- checked using a Microsoft Excel before being transferred to a Windows version of the Statistics Package for the Social Sciences version 24 (SPSS-24). The data was subsequently checked for missing and unengaged responses and then appropriately coded for analysis. Embedded within the questionnaire were reminders to complete all questions before proceeding. As a result, from the completed questionnaires no data was observed as missing.

4.10 Analysis

4.10.1 Qualitative - Thematic Analysis

The policy documents and the open-ended qualitative responses from the staff surveys were analysed by the researcher utilising Braun and Clarke (2006) phases of thematic analysis (see figure 2. below). As described by Braun and Clarke (2006) using these stages was very much a recursive process; which involved much going back and forth, revising and reviewing between stages. The researcher spent substantial time familiarising themselves with the data, examining for patterns and sorting the data into potential themes and subthemes. The researcher employed an inductive approach for the construction of their themes. Through this inductive approach, themes were developed from the data rather than from a preconceived framework (Braun & Clarke, 2006). This ‘bottom-up’ approach means that codes and themes mapped by the researcher during the analysis closely matched the content of the data. It was important to capture the full content of these policies. As such, some themes were more semantic in their construction rather than latent. An example of the refinement of codes towards the generated thematic themes for the service policy documents are represented in Appendix G & H. An example of the refinement of codes towards the generated thematic themes for the staff responses are represented in Appendix I. Coded themes and subthemes were reviewed and discussed with the research supervisor to ensure that the data formed a coherent pattern and the validity of the themes in relation to the entire data set.

4.10.2 Statistical Analyses

Statistical analyses were performed using SPSS Version 24. Descriptive statistics were used to report the sample characteristics with demographic data reported as frequencies and percentages for categorical data and means with a standard deviation for continuous variables. Preliminary analyses revealed no violations of normality. Comparative statistics were conducted using independent sample t-test, and Analysis of Variance (ANOVA), with post-hoc analyses as relevant. Statistical significance was set at $p < .05$, and all tests were two-tailed. The primary dependent variable were outcomes related to the ASQ-ID, as reported above, and independent variables used for categorical stratification included: age (ranges), gender (M/F), training received (Y/N), practising religion (Y/N/Sometimes), awareness of policy documents (Y/N), and whether a policy document was read (Y/N).

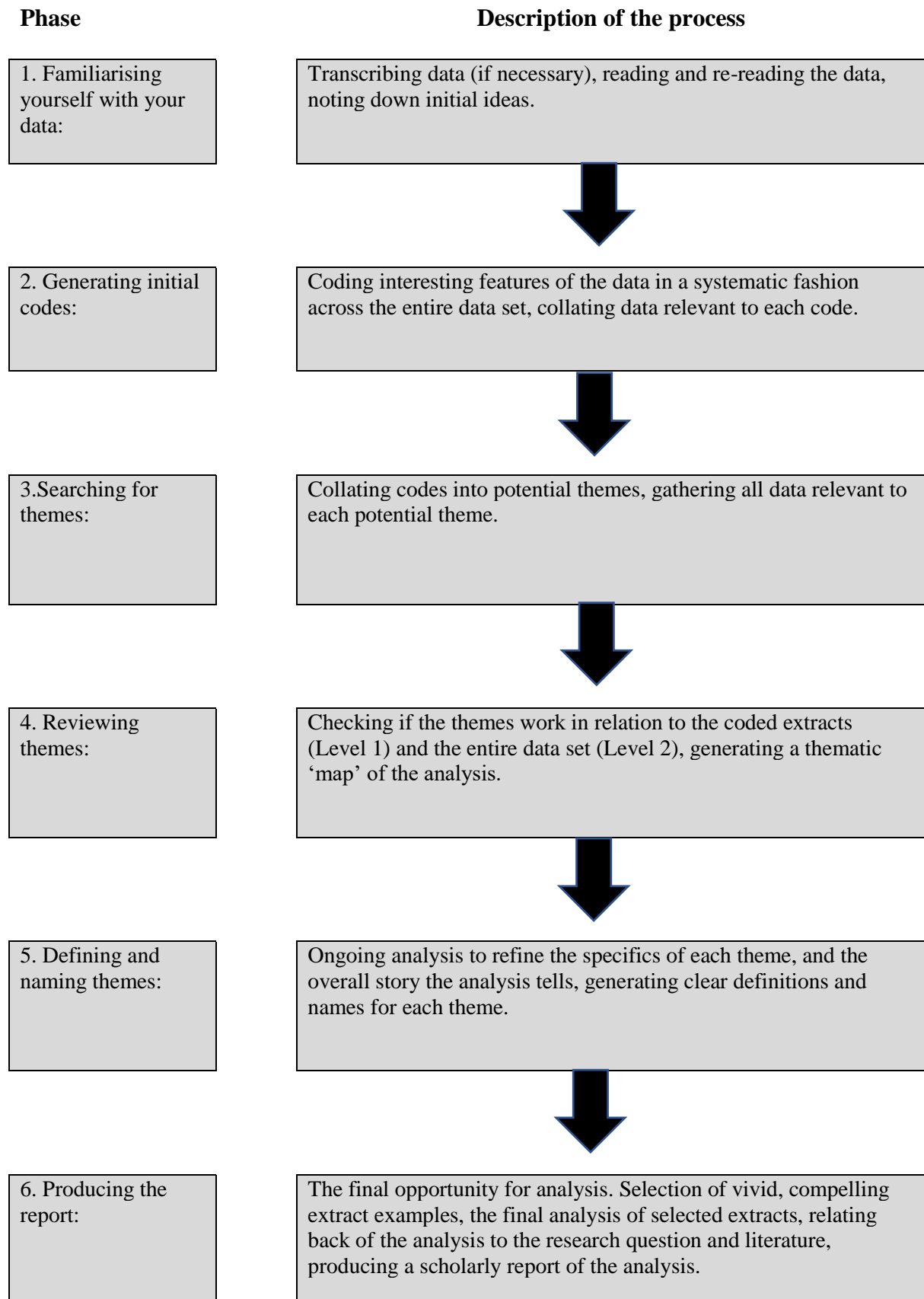


Figure 2. Phases of thematic analysis – adapted from (Braun & Clarke, 2006)

Chapter 5. Findings

5.1 Chapter Overview

The following information was collated from the five service provider policy documents and 86 completed staff surveys. This chapter is broadly divided between three sections. The first section will report on the analysis of the policy documents, exploring the thematic themes from the data. The second section will report on the quantitative results of the staff questionnaire. The final section will report on the open-ended qualitative responses from the staff survey using thematic analysis.

5.2 Policy Documents

Five service providers took part in the study. All the service policies included in this analysis were the policy documents that were available to their staff members as of January 2019. The researcher developed five main themes, with subthemes from the analysis; '*Rights of PWID*', '*Values*', '*Training and Educational Supports*', '*Welfare and Protection*', and '*Supportive Structures*'. These are represented in Figure 3. The thematic analysis of the policy documents was at a semantic and latent level; as such, the themes that were developed reflect these understandings. Each theme is presented in turn and supported by a selection of quotes from the policy documents.

5.2.1 Staff Awareness of Policy Documents

Before reviewing these policy documents, it is worth noting that 62.8% of staff that had 'Relationships and Sexuality' policy documents in their service; stated that they were aware of these documents, while 50% stated that they had read them.

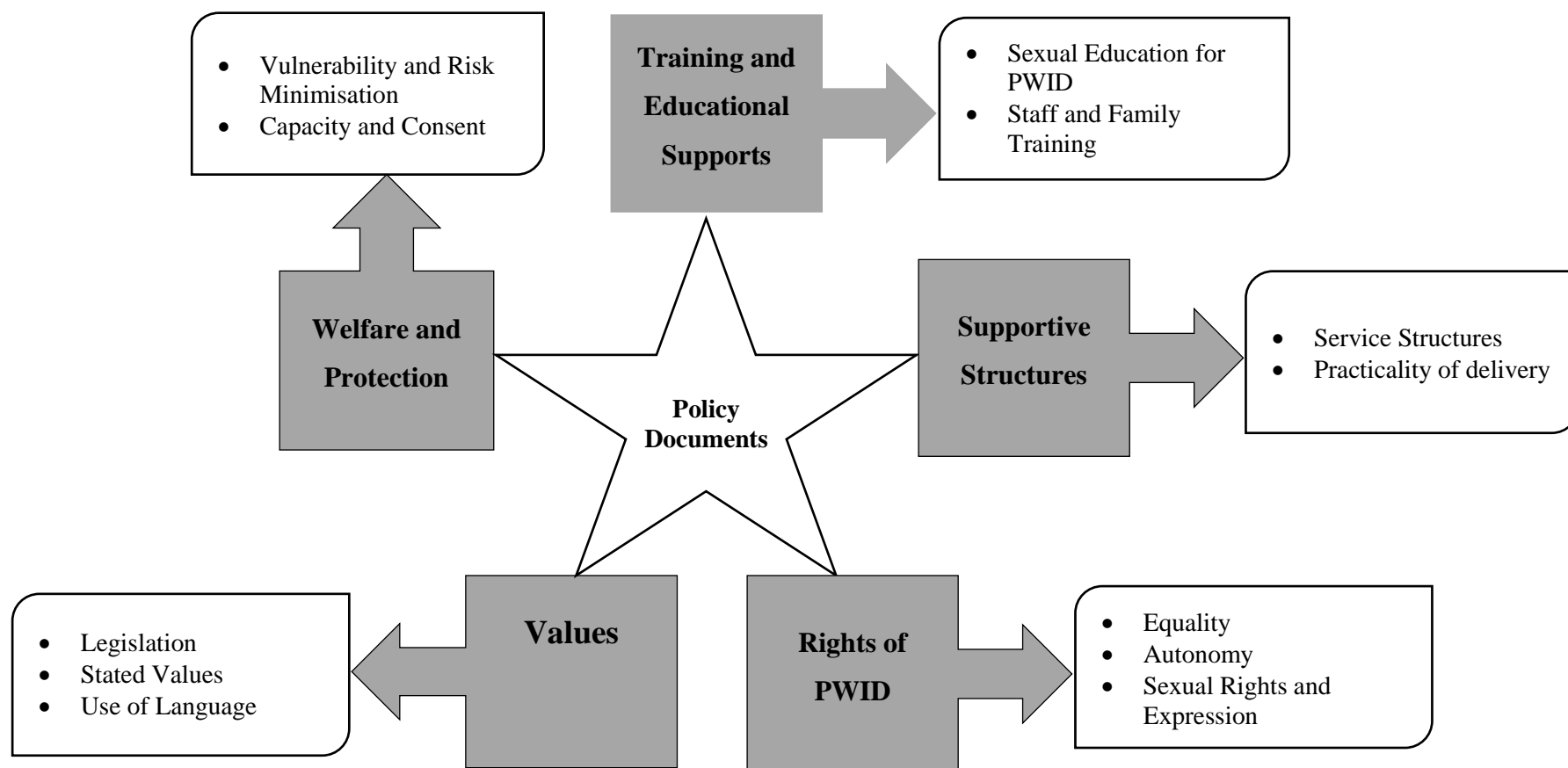


Figure 3. Development of Policy Documents Themes and Subthemes

5.3 Analysis Overview

In exploring these policy documents, it was essential to capture the full breadth of their content, their structure and the language used. The way service providers approach relationships and sexuality can be difficult to assess unless experienced first-hand; however, policy documents can give an indication of these understandings. These can be interpreted through the latent subtexts of the way information is presented, how it is accessed and the due care that is afforded in the construction of the document itself. They can also, as shall be demonstrated, be expressed explicitly in their construction.

5.3.1 Rights of PWID

Several subthemes developed under this theme as the policy documents propagated both the strong promotion of PWID rights while also demonstrating restrictions under the same heading.

5.3.1.1 Equality

Policy documents set out to establish their commitment to support PWID rights in all aspects of their lives. They were strong to reflect on PWID as equal citizens. Collectively, they all set a basis stating their supporting stance to empower PWID to achieve equal lives compared to people without an ID.

“(Service name) exists to empower people with a wide range of learning and associated disabilities to live full and satisfied lives as equal citizens”.

They emphasised that the person should be treated as an individual, not be defined by their disability. Some policy documents demonstrated this equality of expression with their use of language. Referencing “*our*” collective rights, while another policy document did not label PWID. They instead referred to “*people*” for their documentation. This adaption towards ‘people first’ language was related to PWID throughout their text. This ‘people first’ approach developed a sense of empowerment in the text and cemented a position of equality.

“As part of a successful organisational strategy, people themselves, their families, natural supports and staff need to be informed in such a way that they can support people to pursue relationships of their choice as part of natural fulfilment and a normal life”.

However, in other instances, service provider’s use of equality was not as forthcoming. In one such example, a service discussed their limitations towards the use of pornography. They noted that PWID’s access to pornography should be

“in keeping with the ethos of the service as set out in the policy document”.

This understanding demonstrates that PWID's right to select and view pornography of their own choice could be restricted under the terms of the service provider's values and moral positions. This does not equate to a service promoting a position of equal citizenship compared to the general population.

5.3.1.2 Autonomy

The majority of policies were strong to pick up on the PWID's autonomous rights, for example

"Family members, friends, staff, or other interested parties can neither consent nor deny the right to sexual expression of a person with an Intellectual Disability and/or Autism".

In this regard, service policy documents were particularly strong on issues of confidentiality. They reported their intention to uphold the personal information of PWID, especially concerning sensitive issues like those of sexuality and relationships. Services did note that on occasion this information might need to be shared due to perceived risk and safety, however in line with their best practice operations, these details this would be discussed with the individual concerned before doing so.

The autonomy of PWID in relation to their family members was also discussed. Most policies documented that relatives did not have an automatic right to information, or to be involved with the sexual lives of PWID. However, some policies were not as strong in this position. One policy did explicitly relate to the position of the family in relation to the expression of sexual rights and identity. This policy referred to the central role of the family in terms of the decisions for PWID. They delineated that the family had a key role and would be informed of PWID's sexual expression.

"(Service Provider) will recognise and promote the primary caring role of families. Family members will be informed about and involved in all decisions relating to service users' needs in the area of sexuality and relationships, and about how these needs could best be met".

The policy document did later redress this position to some degree by articulating that if PWID "can make" an informed decision not to have their family involved, this would be respected by the service. However, this phrasing implies that PWID must note their decision before confidentiality around sexual issues can be upheld. This position demonstrates this service's position of supporting family viewpoints rather than upholding the autonomy of PWID.

5.3.1.3 Sexual Rights and Expression

Service providers were strong to note their commitment to support PWID in their rights to express their sexuality. Documents detailed the importance of sexuality and personal relationships in everyone's life, and they reflected that the needs of PWID should not be considered different in this regard. Policies noted that staff should support everyone to have opportunities for self-expression and to enjoy relationships. They noted that there was a range of personal relationships that PWID might wish to engage in with others

“Loving human relationships range from pleasures of conversation, simple affection and shared activities, physical closeness, hugs and kisses, and to full sexual intimacy”.

and their position was to support and respect these choices. Policies were also strong to emphasise rights regarding the sexual orientation of PWID. They discussed how PWID should not be stigmatised because of their sexual orientation, and their decisions should be respected by staff.

However, in one policy document it was noted at the end of a subsection on the topic 'homosexuality' there was a reference to *“overt sexual behaviour”*.

“Given the possibility that overt sexual behaviour may arise primarily from loneliness or isolation, opportunities for forming friendships are to be created and appropriate skills developed”.

This was not written in any other part of the policy. Including a sentence like this at the end of their expression on the rights around homosexuality undermines the previous statement, especially when it was not contained in other parts of the document. It creates the impression that homosexuality was a construction of loneliness and a search for friendship rather than identifying it as a legitimate sexual expression.

5.3.2 Values

The theme 'values' was interpreted from the policy documents. Service's positionality in relation to dealing with legislation and their overt and latent references towards the construction of their values are detailed.

5.3.2.1 Legislation

References to the legislation for PWID was a key thread in all service policy documents. Services were keen to remind readers of the *“competing issues”* regarding the national legislation and the recognition of the rights of PWID in the area of sexuality and relationships.

Services particularly noted two legislative documents, the Irish legislated 'Criminal Law (Sexual Offences) Act 1993, Section 5' and the 'United Nations Convention on the Rights of Persons with Disabilities – UNCRPD 2006'. It is contended, that part of the service provider values around PWID and sexuality were based on how they used these legal documents.

Firstly, it was noted that all services recognised that they were restricted by Irish legislation, the 'Criminal Law (Sexual Offences) Act 1993, Section 5'.

“Services responsibility is to ensure that it conducts its activities according to the law of the land”.

Policies recognised that service providers, their staff and PWID needed to adhere to its position or else face the prospect of being prosecuted. However, even with this viewpoint stated some service providers demonstrated their dissatisfaction with the Irish legalisation. Three of the policy documents clearly articulated this view in their texts. In the two other documents, minimum reference was made towards the critique of the legalisation. It is therefore difficult to infer their values based on this topic. However, given their proposed support for the expression of sexual rights in their texts, it is interpreted that their potential critiques of the Irish legislation might be shared.

Three of the policy documents used extracts from the 1993 Criminal Act (or the full text in one case) and critiqued its position. They highlighted numerous shortcomings in the legalisation. They articulated their frustration on the law's interpretation of PWID's “*presumed incapacity*” and the subsequent restrictions towards sexual relations. Policies critiqued the legislative's viewpoints on the required capacity to live an independent life. With policies noting that

“capacity to live independently, and the capacity to consent to sexual relations, is not the same.....It does not recognise that people who may require support to live independently may have capacity to consent to sexual relations.”

One policy was particularly vocal around this issue and strongly detailed their position on the matter by stating that

“Virtually everyone is dependent on others to some degree. On this basis, it could be argued that in receiving a service, every service user is incapable of living a totally independent life. Equally, it could be argued that the majority of service users are capable of living an independent life to some degree”.

It is implied that such strong criticisms of the 1993 Criminal Act would suggest their marked support for its reform and/or repeal. These criticisms can be seen to indicate part of the services underlying values concerning sexuality and intimate relationships of PWID.

In addition to these critiques, one policy was also clear to inform what the 1993 Criminal Act did not restrict, for PWID in their service.

“It is not an offence for men and women to engage in sexual acts which fall short of attempted sexual intercourse or attempted buggery, even if one of the parties is “mentally impaired”.

This example defines this service’s value in promoting the rights of PWID in their sexual expression even under the confines of the Irish legislative system.

As well as providing critical feedback in relation to the 1993 Criminal Act, policies were also seen to combine the use of international legislation to express their supporting views on relationships and sexuality. It was noted that policy documents used legislative frameworks that advocated for the rights and empowerment of PWID. Policies particularly referenced the United Nations Convention on the Rights of Persons with Disabilities – UNCRPD (United Nations, 2006). Direct quotations of this document were used throughout texts to advocate for the sexual rights of PWID. For example,

“Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood”.

In addition, it was noted in two of the policy documents, they had extracts (full text in one case) of the UNCRPD published as the first appendix. The prime placement of these extracts in the appendices of these texts, coupled with the related positive endorsement that the services wrote regarding these international agreements also demonstrates their use of legalisation as part of their values on this matter.

5.3.2.2 Stated Values

In some texts, the ethos and values of the organisations were overt in their construction. One document was noted to state its value base in the opening section.

“The services are based on Christian values, and this policy recognises these principles”.

This Service clearly defined its Christian value base and although reference in the text was made to respect other viewpoints

“It also acknowledges the right of people to follow their conscience, that they will be influenced in their moral outlook by the society, faiths, traditions and culture in which they live, and that their conscience decisions may or may not be in keeping with Catholic teaching”.

The explicit stating and positioning of these Christian values to the forefront of the document very much cemented this position on the reader. Based on the representation of Christian values and culture in an Irish context, it is suggested that this would have a significant impact for the reader. Its inference to the potential restrictions of rights regarding sexuality could be implied. For example, later in the same text, it was noted that

“Staff members have a responsibility to ensure that all materials viewed, read or heard by service users is in keeping with the ethos of the service as set out in the policy document”.

It is suggested that this Christian philosophy demonstrates another element of these service’s values in this area.

In contrast, all policy documents reminded staff of their role to support PWID in their interests and not to force their own values on those they supported. Services recognised that sexual expression could be a sensitive area. However, they stated that it was important that staff did not

“impart their own personal, political, cultural, ethical, moral and /or religious values”.

One policy document outlined that they would provide active support for staff to be more reflective in this regard by having them consider values, culture, race, and age as so not to impact on their work with PWID. Policies noted that staff values on masturbation and sexual orientation were not to interfere in their support of PWID. They noted that Services were to support choices and that

“it is the person as an individual that is our concern”.

In other texts, staff were also reminded to support and respect PWID in their rights to make mistakes in relationships. They noted that PWID should not be impeded in making decisions for themselves and that staff should respect this right. This promotion of rights for the PWID by having staff remain cognisant of their own value base and not impose them on PWID represents a progressive value base for the services in this review.

5.3.2.3 Use of Language

The latent meanings of language expose significant insights into a reviewed document. For most documents in this review, rigid clinical language was used to express relationships and

sexuality with few mentioning the word “love”. However, some texts did adopt to less rigid language. They included more references to terms of “love, passion and connection”. They advocated on the richness and the meaning that personal and sexual relationships can give to those involved.

“They are both a source of, and a means of, expressing intimacy, connection, love, joy, creativity, desire, identity and individuality”

They continued to reference love throughout the text, displaying a degree of warmth and feeling towards the subject matter, rather than a clinical approach. They expressed the equality in being loved and to loving and proclaimed that

“Disability is not a barrier to loving and being loved”.

In using this language, it is suggested that the Services in their policy documents exuded values that actively promoted the whole person and their connections, not just as a legal and protective response.

However, some documents were less informed in their approach to the language they used. For example, under the heading of ‘guiding principles’. One policy noted relationships between PWID as “*special friendships*”.

“Couples who form special friendships should be taught to express themselves in a way that does not embarrass or disrupt the harmony of the group in which they live”.

Defining relationships as “*special friendships*” appears to trivialise these people’s relationship status. It associates it as being companionship, rather than one with the potential for sexual intimacy and therefore it could be suggesting an ‘infantilised’ view of PWID. This use of language is another reference to the conflicting nature of the values that these service policy documents exuded in their content.

5.3.3 Training and Educational Supports

This section will detail the theme of training and educational supports that were constructed in the review of the policy documents. Subthemes relate to the provision of Sexual Education for PWID, staff and family training resources and the clarity of content on the policy documents themselves.

5.3.3.1 Sexual Education for PWID

All service policy documents were supportive of PWID receiving Sexual Education in their services. With policies stating that the provision of information for PWID on sexuality and relationships is central to their role. All services stated that it was the right of all individuals to access Sexual Education and it was their responsibility to provide this information to them.

Service documents recognised the difficulties with providing Sexual Education to those PWID with more severe levels of disability. However, they noted that every provision should be made to support all PWID with their education. With this understanding, they recommended that the provision of Sexual Education should reflect the different needs and different learning styles of PWID, be that through a group or in an individual setting. Service policies also noted that this process should be started early and that it would require ongoing refreshers throughout the person's lifespan.

“Continuous support throughout the person's life, because the retention of information or skills may be limited, and ongoing practice may be called for”.

Policies expressed their intention for openness and transparency with PWID in communicating with them about sexual matters. They recommended that PWID should be free to express their views, experiences and beliefs on the topic. As a result, they recommended staff to support Sexual Education not just in the formal setting, but also to allow for these topics to be explored in naturally occurring settings as they arose.

“attitudes and practices which help to create a responsive atmosphere in which service users can feel secure about their own sexuality and reassured that their feelings are not being devalued”.

5.3.3.2 Staff and Family Training

All policy documents outlined their position to support staff in their training and education regarding relationships and sexuality for PWID. As a result, they stated that the service responsibilities were to

“make sure that information and supports are up to date, accessible and meaningful”.

Policies also stipulated their requirement for staff to keep up to date with current practices and legislation changes. However, it was noted that as per the date of this review none of these policy documents had recorded the change of the 2017 Criminal Act in their document.

Policy documents also outlined their responsibility to provide staff with the resources and training so that they could fulfil their duties and best support PWID. However, there were references in the texts that suggested that this training might not be widespread. For example, one document referenced that “*selected*” staff would receive this training.

In addition, some policies also stated that training should be supported for family members in this area. They recognised the importance of supporting families to understand and encourage the personal and sexual development of their relative through information and education. They emphasised that this position would allow for more trust between services, staff and the families when supporting PWID.

“The establishment of relationships of trust with families is particularly important when sensitive issues arise”.

They noted that ongoing communication and support from services on these issues could help in situations where PWID’s rights conflicted with their family’s wishes.

5.3.3.3 Clarity of Content

It was recognised that policy documents had issues in terms of their accessibility and clarity in their approach. As such their application towards the training and educational supports for staff needs to be acknowledged. Although document length varied between 9 and 13 pages of text, the quality and relevance of their contents varied substantially. For example, one policy document repeatedly referenced the same supports structures for each subheading (masturbation, contraception, sexual health etc.), rather than clearly outline these as general guidelines at the beginning of the document. This resulted in unnecessarily increasing the overall length of the document without adding any further clarity for the reader. It was also noted that service standards and guidelines were ambiguous in their construction. As noted above, policies extensive critique of the legalisation could be seen to leave the reader confused as to their responsibilities in the service. For example, in one document, the policy itself was 5 ½ pages, and the appended critique of the legalisation was equal. This could be seen to leave a reader confused regarding the systems and procedures in place for their service. These are important to note in terms of staff training supports, as accessibility of these documents should be an essential resource.

5.3.4 Welfare and Protection

Policies identified the role of welfare and protection of PWID as a central part in their texts. For example, at the outset of one policy document, the identified that their primary role was to

“provide a framework of protection and reassurance for staff and service users in a sensitive area where the possibilities of misunderstanding and the dangers of exploitation are ever present”.

Indeed, in all the documents, safeguarding and protection appeared to take primacy regarding supporting PWID express their sexuality.

5.3.4.1 Vulnerability and Risk Minimisation

Policies identified the need for PWID to be safe from exploitation and abuse and they particularly referenced PWID’s capacity and consent in this regard. The documents noted that PWID’s lack of knowledge and experience in this area promoted a difficulty for them in calculating associated risk. As a result, they recognised their role to safeguard PWID.

“People with intellectual disabilities are entitled to be safe from personal exploitation, bullying, harassment and from all forms of abuse, including sexual abuse”.

Policy documents recognised that through cognitive limitations associated with their ID, PWID were more vulnerable than the general population. Therefore, they required greater protection from services and their support staff. The policy documents depicted this as a balancing act.

“While acknowledging a person with an intellectual disability’s right to marriage, sexuality and parenthood, it is essential to balance this by protecting those who are vulnerable and incapable of making decisions due to their disability from being manipulated, exploited or abused”.

Policies noted that they should strive to promote the rights of the individual while also protecting them.

“Upholding their rights to freedom and choice has also to be tempered by recognition of their great vulnerability to sexual exploitation, and the services have a clear duty of care regarding their protection”.

It was noted in the documents there was a tendency to gravitate towards the potential for the risk of abuse and exploitation. There was very little documentation on the importance of positive risk for PWIDs in their sexual expression.

5.3.4.3 Capacity and Consent

Policy documents were keen to address the issues around capacity and consent. Services were strong on their statements to assess the vulnerability of people in this regard. They stated their position was to protect against coercion and exploitation of PWID in their care. They noted that it was their responsibility to assess for capacity to consent for those wishing to engage in sexual activities and relationships. They outlined how capacity assessments involved assessing for PWID sexual knowledge around sexual health and contraception and detailed how targeted support would be given to those that required it.

One policy was particularly detailed to explain what it means for an individual to understand both the nature and the consequence of an act and their ability to agree to participate freely. They highlighted the importance to distinguish between informed consent and saying ‘yes’. Reporting that many PWID

“have been taught from a young age to do as they are told and can remain very compliant throughout their lives and they may be easily swayed to agree to suggestions, not in their best interests”.

This was an important characteristic for the policy document to state. It highlighted the PWIDs potential vulnerability in this regard and emphasised how staff should be mindful of these situations in their role.

Overall, policy documents were strong in relaying information regarding capacity and consent. However, it was noted that none of the policy had updated the changes to capacity in relation to the 2017 Criminal Act.

5.3.5 Supportive Structures

5.3.5.1 Service Structures

Policies noted that staff had a responsibility to help PWID make decisions and understand the consequences of their actions. However, they noted that these decisions should not be made in isolation when sensitive or problematic issues of sexuality arise for PWID. Services identified the possible limitations in knowledge and competency of staff regarding sexuality and relationships matters. As a result, the policies noted that front line staff should refer to managers, psychology and social work departments in situations where they felt they needed additional support in their role.

Policies also recognised the importance to access channels outside the remit of the service provider. Policies referred to the importance of outside professionals and advocates in helping PWID make decisions. They noted that PWID needed to have access to seek appropriate advice from external experts, such as, family planning, sexual health clinics, external advocates, and medical practitioners. Some policies explicitly noted that medical advice must always be sought where contraceptives of a medical nature were being considered.

However, in another document, there was the potential for a noted restriction in PWID's access to contraceptives. This policy stated that to access advice on contraception, services required a "request" from PWID who were "sexually active" and this was to be completed in conjunction with "relevant family members". This reference gives numerous insights into this service provider's supportive position around this issue. Its reference towards PWID who "were sexually active" implies that this supportive measure will be considered on a reactionary basis rather than a proactive one. Meanwhile, the reference towards the role of the PWID's family in this decision is seen to undermine the PWID's rights of confidentiality and autonomy in sexual rights.

Under this remit of service supports, one service referenced its approach in supporting pregnancy within its service. It was noted that if a woman in their service intended to get pregnant or faced a crisis pregnancy while attending the service, they could no longer support this person and they would need to find alternative support and accommodation.

(Service Provider) "cannot provide support within its residential services to mothers and babies. It will, in conjunction with families, help any female client wanting to have a baby to access the information and services necessary in order to make an informed decision. A service user living in a Group Home situation will be helped to find more suitable accommodation when this is required, and to consider and make appropriate arrangements for the care of the baby, in association with the HSE and other relevant statutory bodies".

Researcher's Reflection

<p><i>As a researcher, I was particularly taken aback by this section of this policy. My immediate thoughts went to women that I worked with in the past and if they had become pregnant in this service that operated this system. I found this quite distressing to think of an individual having to leave their service and find alternative accommodation. Away from their supportive network of friends, staff and the service which had supported them. This seemed particularly difficult to comprehend as this would be the time that they would most require these supports.</i></p>

5.3.5.2 Practicality of delivery

In these policy documents, there was a noted absence of practical guidance for staff. Policy documents were constructed in an overarching structure, demonstrating large scale philosophical ideals. These were predicated on the previously explored elements of rights, values, protections, and supports. However, there were few mentions of day-to-day issues that staff regularly face in their Services. They offered staff little to no practical detail on working with issues like pornography, dating, inappropriate touching of others, etc. There was no mention of the use of the internet, regarding internet dating sites, social media and online pornography. This might be reflective of the age of these documents. However, they do represent a failing on their part to monitor and support the changes in society and the potential practical needs for staff in these positions. In addition, there were no practical guidance or references towards supports that would help PWID increase their social friendships and potential for dating relationships. It is essential to capture these missing details in these policy documents, as their absence shows neglect of the necessary supports for staff in supporting PWID.

5.4 Staff Survey

A summary of the ASQ-ID results is presented in Table 4 below. Table 4 outlines the four predefined factors/subscales; Factor 1: Sexual Rights (13 items); Factor 2: Parenting (7 items); Factor 3: Non-Reproductive Sexual Behaviour (5 items); and Factor 4: Self-Control (3 items). A full listing can be seen in Appendix J.

Table 5. ASQ-ID Total and subscale scores (n=86)

ASQ-ID Scores	Potential Range	Sample Range	Mean (SD)
ASQ-ID Total Score	0-170	65-134	109.1(17.3)
Sexual Rights	0-65	28-64	48.2(8.1)
Parenting	0-35	10-35	26.9(6.0)
Non-Reproductive Sexual Behaviour	0-25	13-25	21.6(3.6)
Self-Control	0-15	6-15	12.4(2.5)

5.4.1 ASQ-ID Analysis

A series of ANOVAs were conducted to investigate whether there was a significant difference within the group when stratified on categorical variables of staff member's gender, age, education, practising of religion, training, and their awareness and reading of service policy documents with the ASQ-ID total scores and subscales. Table 6. below represents the mean ASQ-ID total and subscales scores on selected dependent variables.

5.4.1.1 Gender

Participant gender was not found to be a significant contributory factor when comparing the ASQ-ID total scores, or the individual subscales. Males $M=108.31$, $SD=4.71$; Females $M=109.3$, $SD=2.03$; $F(1,84) = 12.700$, $p=.838$.

5.4.1.2 Staff Age

Participants during the survey self-selected their age from one of the five categories (18 - 25 years; 26 - 35 years; 36 – 45 years; 46 – 55 years; 56 – 65+ years). There was a statistically significant difference for the subscale Non-Reproductive Sexual Behaviour. Post hoc comparisons (Tukey) indicated that the mean score of 18 - 25 years was significantly different to 46-55 years. $M=24.20$, $SD=1.23$; $M=19.75$, $SD=4.08$, respectively; $F(4,81) = 3.989$, $p = .005$. There were no significant differences in the ASQ-ID total scores. These results suggest that older participants had more conservative attitudes towards PWID's non-reproductive behaviour, compared to younger participants.

5.4.1.3 Level of Education

Participants during the survey self-selected their education level from one of the four categories (Secondary School; Third Level Cert/Dip Level 5/6; Undergraduate level 7/8; Postgraduate Level 9/10). There was a statistically significant difference for the ASQ-ID total scores. Post hoc comparisons (Tukey) indicated that the mean score of Postgraduate Level 9/10 was significantly different from Secondary School. $M=115.07$, $SD=14.42$; $M=87.00$, $SD=22.64$, respectively. $F(3,81) = 4.289$, $p = .007$. There were also significant differences on the subscales, with Postgraduates Level 9/10 compared to Secondary School education on Sexual Rights, $F(3,81) = 3.639$, $p=.016$; Parenting, $F(3,81) = 4.563$, $p=.005$; and Self-control, $F(3,81) = 3.484$, $p=.020$. These results suggest that participants who had higher educational levels had more positive attitudes towards PWID's sexuality than individuals with lower educational levels.

5.4.1.4 Practising Religion

This comparison found that people who self-reported that they actively practised their religion were statistically different on the subscale Non-Reproductive Sexual Behaviour to staff who did not practice their religion. Post hoc comparisons (Tukey) indicated that the mean score of those actively practising their religion was significantly different to those that did not actively practise their religion. $M=19.72$, $SD=3.76$; $M=22.67$, $SD=2.54$, respectively; $F(2,83) = 6.586$, $p = .002$. These results suggest that participants who practiced their religion had more conservative attitudes towards PWID's non-reproductive behaviour compared to participants who did not practice their religion.

5.4.1.5 Received Training

This comparison found that people who received training were statistically different for on ASQ-ID total scores to staff who did not receive training. Post hoc comparisons (Tukey) indicated that the mean score of those that received training was significantly different to those that did not receive training. $M=116.67$, $SD=12.54$; $M=107.12$, $SD=17.88$, respectively; $F(1,84) = 4.525$, $p = .036$. There were also significant differences on the other subscales, with those that received training compared to those that did not receive training on Parenting, $F(1, 84) = 4.360$, $p = .040$; and Self-control $F(1,84) = 4.525$, $p = .005$. These results suggest that participants who received training had more positive attitudes towards PWID's sexuality compared to participants who had not received training.

5.4.1.6 Aware of Policy and Read Policy

Participant policy awareness was not found to be a significant contributory factor when comparing the ASQ-ID total scores, or the individual subscales. Policy Awareness $M=108.31$, $SD=4.71$; Lack of Awareness of Policy $M=109.3$, $SD=2.03$; $F(1,84) 12.700$, $p=.838$.

The comparison for people that had read the policy document was statistically different for the ASQ-ID total scores to staff who did not read the policy documents. Post hoc comparisons (Tukey) indicated that the mean score of those that read the policy document was significantly different to those that did not read the policy document $M=114.63$, $SD=12.6$; $M=103.60$, $SD=19.55$, respectively; $F(1,84) = 9.636$, $p = .003$. There were also significant differences on the other subscales with those that read the policy reporting compared to those that did not read the policy on Sexual rights, $F(1, 84) = 6.073$, $p = .016$; Parenting, $F(1, 84) = 9.492$, $p = .003$; and Self-control $F(1,84) = 9.636$, $p = .002$. These results suggest that participants who read

their service's policy documents had more positive attitudes towards PWID's sexuality compared to participants who had not read these policy documents.

Table 6. Mean ASQ-ID total scores and subscales on selected dependent variables (n=86)

Dependent Variable (n)	Full Scale	Sexual Rights	Parenting	Non-Reproductive Sexual Behaviour	Self-Control
Gender					
Male (70)	108.31	47.94	27.01	21.25	12.06
Female (16)	109.3	48.3	26.81	21.67	12.51
Age					
18 - 25 years (10)	115.90	50.30	29.30	24.20	12.10
26 - 35 years (22)	110.68	48.90	26.91	21.72	13.14
36 – 45 years (25)	112.84	50.00	28.16	22.30	12.40
46 – 55 years (20)	99.45	44.40	23.96	19.75	11.35
56 – 65 years + (9)	108.89	47.89	26.89	20.55	13.56
Level of Education					
Secondary School (4)	87.00	38.50	19.75	18.50	10.25
Third Level Cert/Dip (21)	110.43	48.96	26.05	22.96	12.48
Undergraduate (32)	105.30	46.51	25.77	21.22	11.77
Postgraduate (29)	115.07	50.72	29.41	21.51	13.41
Religion					
Practiced religion (25)	102.24	45.64	25.20	19.72	11.68
Did not practice religion (34)	113.38	49.85	28.05	22.68	12.79
Sometimes practiced religion (27)	110.11	48.85	26.89	21.96	12.67
Training					
Received training (18)	116.67	50.78	29.44	22.56	13.89
Did not receive training (68)	107.12	47.56	26.18	21.39	12.04
Policy Documents					
Read policy (42)	114.63	50.32	28.77	22.28	13.26
Did not read policy (44)	103.60	46.14	24.96	20.91	11.60
*significant differences noted in bold					

5.4.2 Understanding of the New Legislation

In the survey, staff were asked if PWID were allowed in law to have sexual intercourse with other PWID. They were asked the same question regarding people without an ID. Their answers are represented in figure 4. below. Most staff noted that the person's capacity and consent was a key determinant in answering this question. With some staff providing references to the updated 2017 legislation.

"A 'protected person' can now have a sexual relationship with someone if they have the capacity to consent"

However, numerous staff members still referenced the 1993 Criminal Act and they noted that PWID were required to be married to engage in sexual intercourse. While others answered the question from a more personal stance and articulated their personal beliefs without reference to legality.

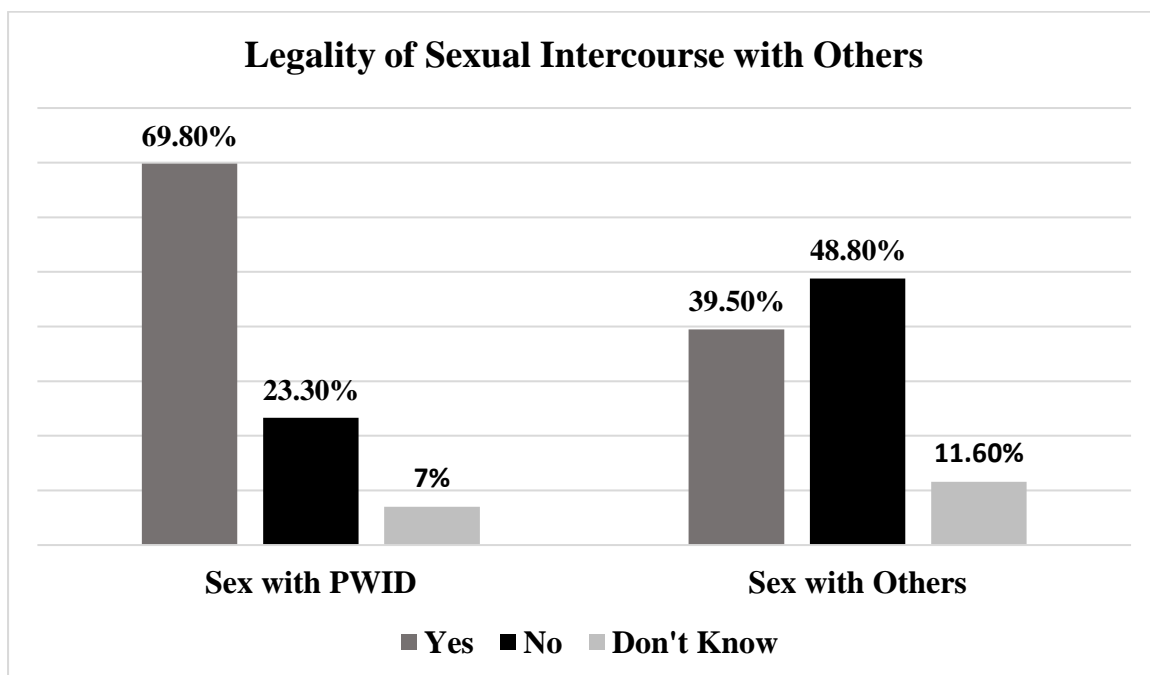


Figure 4. Legality of Sexual Intercourse with Others

5.5 Staff Survey Qualitative Responses

Staff member's qualitative responses from the survey were analysed using thematic analysis. Three central themes and subthemes were developed from the data. These include: '*Unsupported and Frustrated*', '*Taboo Subject Matter*' and '*PWID Vulnerability and Access to Education*'. These are represented in Figure 5. Each theme is presented in turn and supported by a selection of quotes from the staff responses.

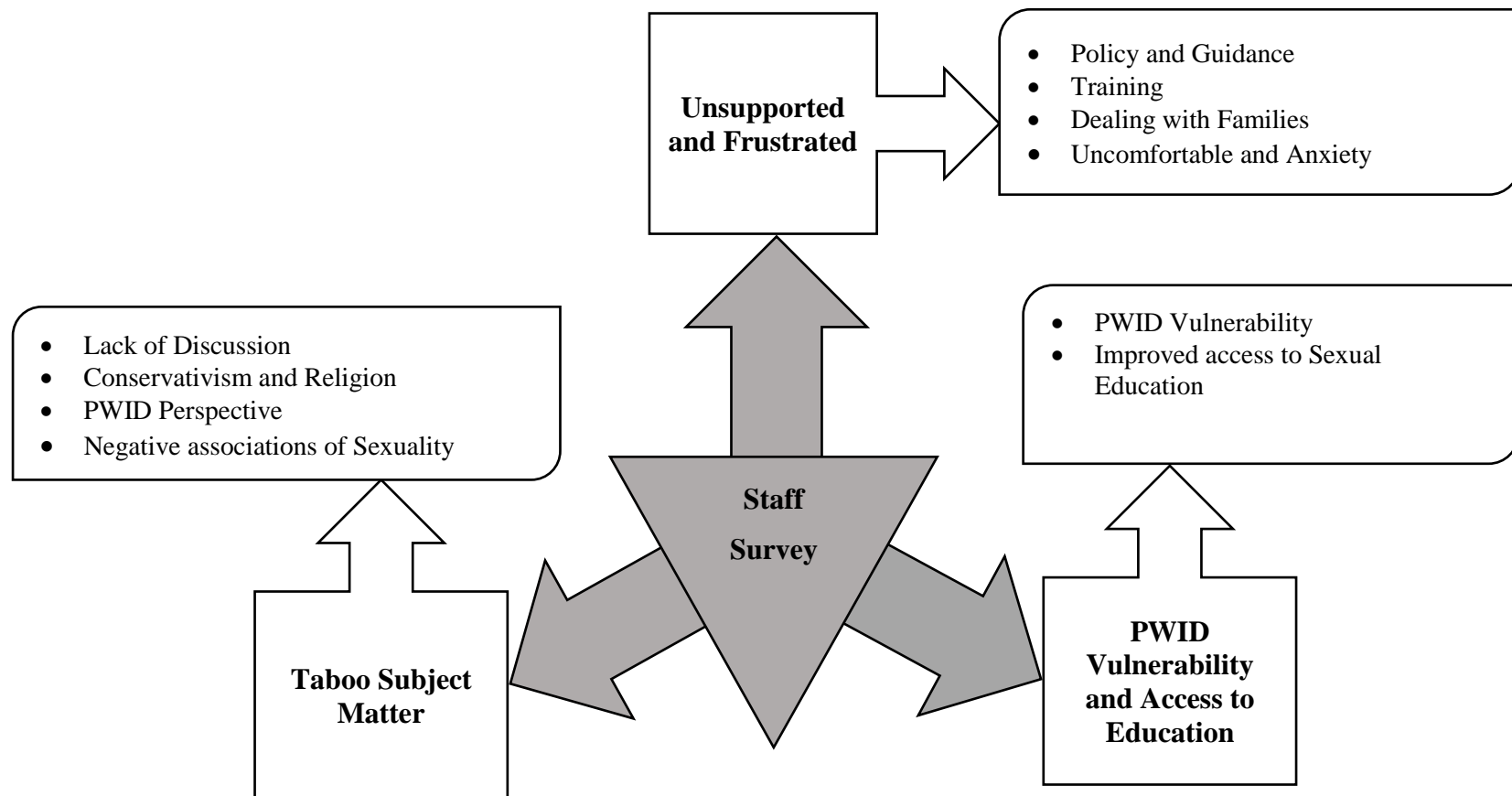


Figure 5. Development of Staff Survey Themes and Subthemes

5.5.1 Unsupported and Frustrated

Staff members identified with feelings of being ‘*unsupported*’ and ‘*frustrated*’ when working with issues of sexuality and intimate relationships.

5.5.1.1 Policy and Guidance

They spoke about feeling unsupported by their management structures in their services, reporting about a lack of guidance in dealing with day-to-day issues. They reported that policy guidance in this area was “*unclear*” and “*restrictive*”, with some staff stating that their service policy

“doesn't reflect what we do in the house”.

Staff reflected that they found this conflicting situation regrettable. However, because of their perception of poor service guidance and restrictions, they found it necessary to work under their own initiatives. These understandings highlight how service guidance and the practical day-to-day application in the services might not be one and the same.

Staff also stated they found the policy in their services to be out of date in both its age and its approach. With one staff noting that they

“read it on induction, some 8/10 years ago. Before completing this (survey), I looked again at the policy. It hasn't been updated in that time”.

This account is supported by the policy review dates already noted in this study. In addition, frontline staff also noted in the past when they had sought clarity from management and MDT members, that this was not always forthcoming. They reflected that they were often left to work under their own initiative.

5.5.1.2 Training

Staff consistently noted the lack of training as their main grievance with services included in this study. They cited the provision of training as one of the critical elements for improving their capacity to work with these matters. However, they reported a lack of emphasis in services to support such training, with time and resources instead promoted towards other service initiatives. Staff spoke about their frustration about not being able to access training even when they expressed a wish to attend these events. They referenced the basic need for such training in their work.

“I cannot get a place.... I have heard of a HSE programme, but this was limited to only 3 places from our Service. All staff should have training. It’s a basic need in our work”.

They described how they would often seek outside training resources as they felt they would not get the required training in their own service.

“I sought this out myself. None has been offered in the Service I work in for many years”

These limited training resources available to staff members are clearly represented with 20.9% reporting that they had received training regarding sexual and intimate relationships for PWID (see figure 6). With this training taking place mean 34 months (SD = 61.9) previous. However, of the staff that had received training, 83.3% of them found it beneficial.

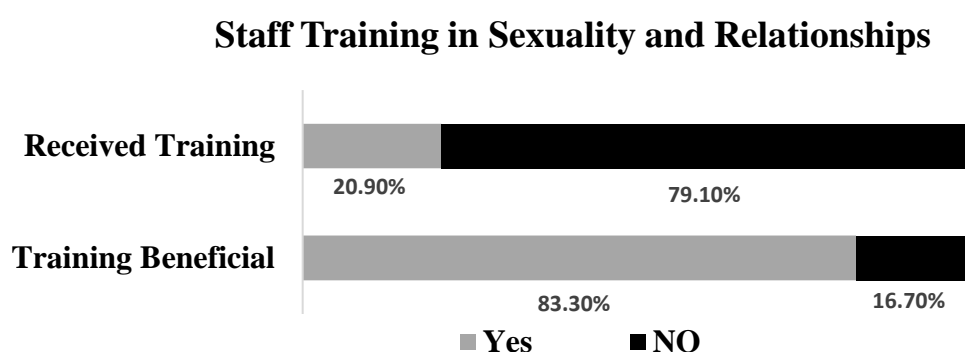


Figure 6. Staff Training in Sexuality and Relationships

5.5.1.3 Uncomfortable and Anxiety Provoking

Staff recorded responses of feeling uncomfortable working with issues relating to intimate relationships and sexuality. They reported their internal conflict of wanting to protect the individuals they supported while also promoting their autonomy. They detailed how they were

“afraid of what would happen if they started a proper relationship with someone”.

Part of their fear and anxiety was described as coming from working with PWID without adequate resources and training. They noted that this lack of training made them feel uncomfortable in dealing with issues. They felt underprepared to work with the people that they supported and as a result they commented that a

“A lot of support and training is required to increase staff members confidence levels in supporting service users with sexuality”.

In addition, staff also reported feelings of embarrassment around talking about the subject matter with PWID and other staff members.

“Sometimes, it can be embarrassing, especially with men and masturbation. But I think with more talking about it and getting used to it we can become more comfortable with working on these issues”.

Staff again highlighted how improved training and dialogue in this area could offset these feelings of embarrassment.

5.5.1.4 Dealing with Families

Staff reported they felt particularly let down in terms of obstacles that they faced when dealing with PWID’s family members. They acknowledged that this could be a difficult position to negotiate, as they recognised the primary role that families have with PWID in their services. However, they noted that family’s views could be quite restrictive with this subject matter and that this had often led to families either flat out saying “no” or else relaying their noted fears to management. As a result, staff reported instances where they felt that their service did not back them in their support of the PWID’s rights and instead complied with family wishes.

“we have seen how we have followed family opinion around these issues”.

They reported feeling frustrated with their services, expressing that they felt unsupported in their role. Staff stated that they required more support in their role from services to help PWID achieve their relationship and sexuality rights when working with families. They stated that

“service needs to be person led, not family interest”.

5.5.2 Taboo Subject Matter

Staff recorded that sexuality and relationships were very much under-discussed in services. They described it as being very much a “*taboo subject matter*”. With one staff remarking that they were so

“so glad (that this study was) shining a light into this subject matter, which largely exists in whispers and covert documents”.

5.3.2.1 Lack of Discussion and Recognition

Staff noted that this position was predicated on the history of the services and the culture in which it operated. They recorded that there was a longstanding standard of secrecy on the

subject and these were coupled with the traditional past restrictions associated in the services. Staff reported how PWID

“were told in the 80's 'don't be at yourself because 'that's dirty', you'll get AIDS (older persons who use the service will tell you this)”.

Such reflections represent the underlying view of how PWID in services can still understand their own sexuality in respect of the previous culture. This perception could also be seen that these reflections are still commonplace and perhaps little has changed for those PWID in those intervening years to change this viewpoint.

Staff also spoke about how intimate relationships and sexuality were not being referenced in the PWID's overall quality of life for the individual

“Services...support people to have a good and meaningful life as long as it doesn't include intimacy, sex, babies etc”.

Staff noted that services and staff members often focused on companionship instead of helping the person develop intimate relationships. They reported that care plans did not contain information about the PWID's relationship and sexuality. Instead staff referenced that

“plans are for platonic relationships”.

Figure 7 below represents this viewpoint. This question of the inclusion of intimate relationships in 'care plans' recorded a pronounced response among the staff taking part in the survey. They noted their own shock in realising that they had never seen 'intimate relationships' recorded in the 'care plans' in their service.

“I have never seen it mentioned in any - it's actually shocking when you think about it”.

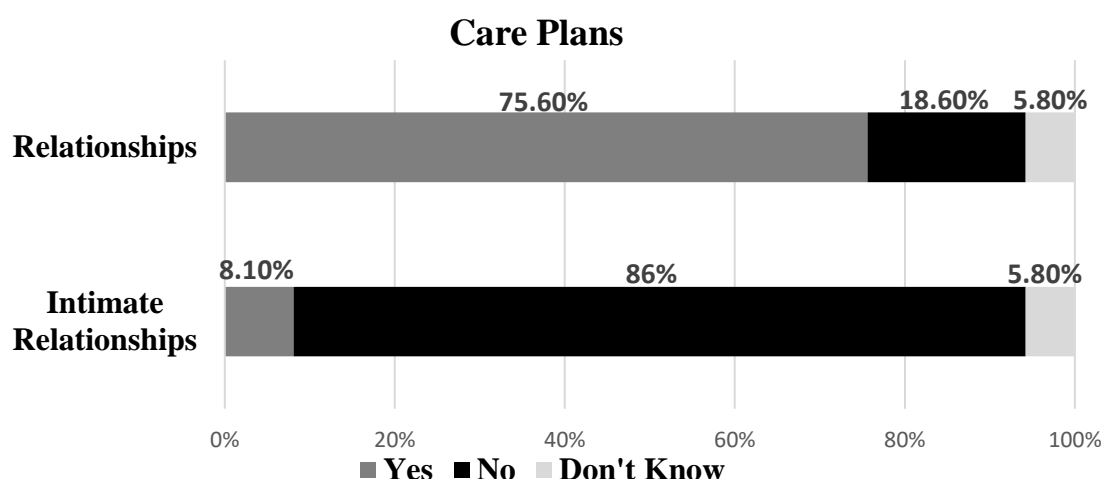


Figure 7. Relationships and Intimate Relationships in ‘Care Plans’

Staff also discussed that although relationships and expression of sexuality was a taboo matter. When it came to homosexuality, the door was firmly closed. Staff reported that homosexuality was never discussed, that this topic was way too sensitive for their services.

“Being gay is never even mentioned as a possibility. Sad but true”.

Staff felt that there would not be meaningful support for PWID who identified as being homosexual in their Service

“If LGBT - not a hope of meaningful support”.

5.5.2.2 Conservatism and Religion

Staff spoke about the conservative philosophy of their service providers. They detailed how religious teachings were very much part of the historical culture, and these viewpoints still existed in services today. They discussed how the religious and cultural history created a closed dialogue around this subject matter

“It reveals much about our own attitudes as an organisation. Don’t tell people as it will enrage the conservatives and the church”.

One staff member recorded their opinion that perhaps older staff members have more restrictive viewpoint considering their cultural upbringing in Ireland.

“Older staff have less ability in this area probably due to our own repressive & restricted upbringing”.

Staff recorded their want for more open discussions around relationships and sexuality and for services and staff not to block these types of conversations. They noted that these discussions should be at both the local and national level. A staff member noted that perhaps Ireland has changed culturally and there is more openness for these types of discussions.

“The church has lost some of its iron grip on the state and it should be easier to open discussions about relationships and sexuality for people with an intellectual disability”.

5.5.2.3 PWID Perspective

Staff expressed their frustration at the “taboo” nature of this matter. They discussed their recognition that

“It’s a human desire to be loved emotionally and physically, we need to give the people we support an opportunity for that”.

However, they reflected how the lack of open discussion had repressed PWID’s expression of sexuality. They reported that a lack of conversations on the matter has led to restrictive and less open and positive supports for PWID. Staff noted that this was leaving PWID to express their sexuality

“In a hidden manner, scared of being criticised and ridiculed”.

They stated that services are doing PWID an injustice in this area. Staff recorded that PWID’s already historically sheltered life was further being curtailed by the failure of services to have open, honest and constructive conversations on these matters. They recognised that staff would only become more comfortable working with these issues when more open dialogue is generated on this matter. This would also allow PWID to become more capable of making more informed decisions.

5.5.2.4 Negative associations of Sexuality

Staff reported that when issues around PWID’s sexuality were discussed these were often reported to be about negative experiences. They stated that sexuality was usually discussed in services in relation to crisis support meetings because of inappropriate behaviours.

“I support people when issues arise around the appropriateness of masturbation, usually when a difficulty has arisen. Almost always a reactive rather than a proactive response”.

Staff observed that references to PWID’s sexuality were usually found in their ‘Behaviour Support Plans’, where staff focus would be on limiting behaviours through different strategies. Issues around inappropriate masturbation, public nudity and inappropriate touching were cited

among staff. Staff also reported that this reactionary method of sexuality occurred in relation to their Sexual Education. They remarked that PWID were usually given Sexual Education instruction as a reactive strategy to behaviours. Staff expressed their frustration that very little was done proactively in this regard.

“Service users need sex education.... everyone should have an opportunity to get this...I have seen one or two instances where service users got this, but it was for challenging behaviour”

Staff did record a few positive associations around PWID’s sexuality, with limited references to hand-holding and kisses on the cheek with other PWIDs. However, they noted that PWID’s main form of sexual expression was masturbation in their bedroom.

“They have the opportunity to spend time in their bedroom whenever they wish”.

5.5.3 PWID Vulnerability and Access to Education

Staff recognised that their work in this area was very much a “*safety vs autonomy*” issue. They expressed their insight on the potential vulnerability of PWID and they also recognised that Sexual Education for PWID was a key protection in this regard.

5.5.3.1 PWID Vulnerability

Staff generally supported PWID to engage in relationships and noted that it was an essential aspect of the person’s rights. However, they reflected on their conflicting views on this issue concerning the person’s level of ID, with staff stating their specific concerns about people with severe and profound ID.

“They are very vulnerable, and I don't think they have the capability of understanding sex and relationships. Even others with moderate ID would struggle. It is hard to think about supporting them without giving protecting them”

Staff also expressed their feelings around vulnerability when considering if PWID in their service would have children. They noted that

“I just wouldn't know how a person with ID would cope in that situation or be supported in helping to bring up this child or children”.

They reflected that PWID in their services would need considerable support with these issues.

5.5.3.2 Improved access to Sex Education

Staff demonstrated the need for PWID to be further resourced in their knowledge on sexual matters and called for services to offer

“educational materials to further advance understanding so that they can express their sexual feelings in a safe environment”.

They cited the need for PWID to receive sexual education and underlined its value in taking place before PWID entered Adult ID Services. Staff stressed that the importance of early education that continued throughout their lifespan would be the most beneficial.

“Sexual education should be a gradual process that starts when the person is young and is taught about his/her own body and continue on from there. Every opportunity to share with the person should be utilised”.

They noted that this should be recursive, building upon the person’s skill level and that every opportunity for sharing of knowledge and information on this subject area should be taken. They recognised that providing PWID with educational supports in these matters would lead to greater information and therefore protection against potential abuses.

“People need support and education around making decisions”.

5.6 Chapter Summary

This chapter reported on the main findings from this study. It detailed the five themes that the researcher developed from the review of the service provider policy documents and the three themes from the qualitative survey answers, both with subthemes and illustrative examples provided in the form of direct quotations. It also reported on the quantitative data from the staff survey responses. The implications of these different sections will be reviewed accordingly in the discussion chapter.

Chapter 6. Discussion

6.1 Introduction

This chapter provides a critical discussion of the study's primary findings with reference to the relevant literature discussed in Chapter Three. For clarity, it will broadly follow the same three sections in the Findings chapter; the policy documents, the quantitative findings and the staff member's qualitative responses. There then will be an integration of these findings. This will be followed by a critical review of the ethical processes; and the strengths and limitations of the current study. The chapter will then outline suggested recommendations for future policy, clinical practice and avenues for future research in this area. The chapter concludes with a summary of the study and the researcher's personal reflections.

6.2 Policy Overview

Through the themes that were developed in the findings of this study, it is suggested that policies demonstrated a conflicting message. The reviewed documents were interpreted to postulate certain viewpoints only to counter these with different viewpoints in later parts of their texts. The reported themes from the Findings chapter support this overall understanding.

6.2.1 Theme 1 - Rights of PWID

Service policies propagated their support for the rights of PWID in terms of equality, autonomy and sexual rights. Only for these viewpoints to be curtailed or restricted in later parts of their texts. For example, detailing positions that advocated for the equality of PWID as equal citizens, were subsequently, countered by service restrictions regarding equal access to pornography due to service ethos. In addition, the supports for the rights of PWID's autonomy were seen to be overshadowed by some documents overt reference to the position of the family's role on PWID's expressions of sexuality. Furthermore, the supports for PWID regarding their sexual rights in terms of sexual intimacy and sexual orientation were also conflicted; with some reducing homosexuality to a construction of loneliness and friendship.

It is contended, that although these policies propagated their support for rights of PWID, the subsequent mixed messages undermine this position. It is suggested that these descriptions would leave staff confused on the positionality that services hold on these issues. Previous research has documented patterns of staff confusion on policy documents offered by services (Ćwirynkalo et al., 2017; Hollomotz, 2009; Ryan & McConkey, 2000). However, this literature

has not defined the specific details of these conflicting messages, due it not being their study's aims.

6.2.2 Theme 2 - Values

Service providers constructed similar mixed messages regarding their value system. It was interpreted that policies demonstrated service provider values in supporting the expression of sexuality for PWID; with their criticism of the 1993 Criminal Act, their explicit detailing of what the 1993 Criminal Act did not restrict, and with their promotion of the UNCRPD. In addition, policy statements promoted staff to be reflective of their own morals and attitudes. It is suggested that this further demonstrates their values in upholding the rights of PWID. Furthermore, some services also expressed their supportive values with their use of language, which reflected love, connection and warmth. Such references embodied person-centred values that promoted the individual rather than a legal and protective response.

However, in contrast, overt statements towards the religious ethos of the organisation demonstrate a different value base. Research indicates that Christian philosophies can be restrictive in their thought processes around sexuality (Gardiner & Braddon, 2009; Lafferty et al., 2012). Such explicit references to this ethos can have a significant bearing on the subject matter.

It is asserted that these service policies delivered contrasting viewpoints on their value system. Their promotion of positive values in terms of legislation, staff awareness of attitudes and use language was potentially overshadowed by their explicit reference to Christian ethos and its resulting connotations.

6.2.3 Theme 3 - Training and Education Supports

All policy documents defined the need for all PWID to receive Sexual Education. Similar to previous research, they indicated that Sexual Education should be recursive and extend throughout the person's life (Dukes & McGuire, 2009; McDaniels & Fleming, 2016). Particular reference was made for this education to be inclusive so that those with severe and profound IDs could be accommodated with the appropriate supports.

Policy documents also captured the need for staff to be trained in this area. However, their reference that "*selected*" staff would be accommodated for training was interpreted to suggest that services will provide training where necessary, and to those, where needed. By allocating training on a selection basis, rather than as standard, there is the potential for a

significant impact on service provision regarding sexuality. Research has reported that a lack of training in this area, will result in staff being underprepared, under-resourced and therefore less capable of giving quality information to PWID (Bernert, 2011; Wilson et al., 2011). Furthermore, untrained staff have also been shown to have more conservative attitudes towards sexuality for PWID than trained staff (Pebdani, 2016).

In addition, to these training supports, it was also noted that the clarity of the policy documents was ambiguous. Repetition, document length and use of language were all noted to distract from the overall content as an educational resource.

It is suggested that service policies on the topic of education and training were positive in outlining their provision of Sexual Education, however their reference to “*selected staff*” training and their overall clarity of content limit these resources.

6.2.4 Theme 4 – Welfare and Protection

Welfare and protection of PWID was developed as a dominant theme in the analysis. Service policies strongly demonstrated their role in protecting the vulnerability of PWID that they supported. This understanding is acknowledged by previous research, which has detailed that services need to provide protection, and safety from abuse for PWID in relation to intimate relationships and sexuality (Yool et al., 2003; Young et al., 2012). Policies stated how providing this protection together with PWID rights of sexual expression, was a difficult balancing act. A feature that is represented in the literature (Brown & McCann, 2018; Grace et al., 2017). Policies also detailed practical guidance on the concepts of capacity and informed consent. This guidance was interpreted as a proactive measure to aid understanding of the role of safeguarding PWID’s vulnerability.

However, there was a noted absence of ‘positive risk’ for PWID in the construction of these service policies. It is contended that in the absence of ‘positive risk’ initiatives, there can be a focus on risk minimisation and a system that generates a protectionist attitude. Research by Tindall (2015) suggests that this focus on safeguarding processes has the potential to create a climate of “*liability avoidance*” that inhibits PWID’s sexual expression. Other researchers suggest that risk minimisation for PWID has resulted in subtler types of restrictions for PWID than those experienced in the past (Bates, Terry, & Popple, 2017). Interestingly, an Irish advocacy group on the construction of restrictive practice has proposed that “*Overly Risk Averse*” be defined as a method of restrictive practice (National Institute of Intellectual Disability Studies, 2019). They state the following

“More common and less obvious restrictive practices are where organisations are overly risk averse and prevent a person from partaking in an activity that might involve a level of risk”.

It is therefore suggested that current service provider protocols, under the guise of protection and welfare, might be in fact, restricting PWID in their care by inhibiting their sexual expression. With such an understanding it is suggested that service providers need to be cognisant of their practices and become more aware that protections and safety is just one aspect of service provision.

Overall, it is asserted that the service policies in this review offered strong references towards welfare and protection; however, there was a distinct absence of ‘positive risk’. The safeguarding of vulnerable PWID is of paramount importance; however, there is a need for policies to challenge their dominant views on protection and safety.

6.2.5 Theme 5 – Supportive Structures

Policies outlined the supportive capacity of managers and other allied health professionals to all staff. In addition, they emphasised the role of outside contributors to the provision of care regarding medical issues, contraception and sexual health. However, it was also noted that services could also restrict in this regard. The analysis documented how access and confidentiality regarding contraception were not presumed as an automatic right. Most alarming was one service provider’s response to PWID pregnancy; which suggested that alternative service care and accommodation would be sought for the women concerned. These unsupportive texts are interpreted to have a significant implication for service practice.

In addition, the lack of practical reference in the policy documents was noted. Large scale philosophical ideas and overarching frameworks left these documents void of helpful information regarding masturbation, pornography and the use of the internet. They also failed to demonstrate practical supports that would promote social friendships and the potential for intimate relationships. Previous research has noted that policy documents tend to be unpractical as standard (Cambridge, 2006). However, it is suggested that such a position leaves staff vulnerable to their own interpretation. Cambridge (2006) outlines that policies can only succeed if there is a clear link to the day-to-day issues that staff face on the ground. Other researchers report that policies should be linked to staff training and need to be reviewed and updated to reflect changes that are experienced on the ground (Grace et al., 2017).

It is asserted that the constructed service supports again deliver mixed messages in their content. Services detailing supportive steps in terms of internal and external supports are

contrasted with stated positions of limited access to supports, issues of confidentiality, and unsupported pregnancy arrangements. These are further enhanced by the absence of practical guidance in the documents themselves.

6.3 Quantitative Results

Staff responses on the 'attitudes to sexuality' questionnaire were found to be similar to previous research in the area.

Those in the youngest cohort reported a more liberal view compared to those in the second oldest cohort in their attitudes towards PWID masturbation and homosexuality. These findings correspond with other studies that have reported that older staff can have more conservative viewpoints than younger staff around these issues (Aunos & Feldman, 2002; Cuskelly & Bryde, 2004). Previous Irish research by Evans et al. (2009) have suggested that this older cohort's conservative viewpoint might be linked to their traditional Irish upbringing.

The questionnaire also indicated that those who had completed postgraduate education had more liberal attitudes compared to those with secondary level education. Previous studies have reported similar attitudes based on staff educational levels (Cuskelly & Bryde, 2004; Saxe & Flanagan, 2013).

Participants that practised religion had more conservative viewpoints compared to those that did not practice religion in their attitudes towards PWID masturbation and homosexuality. Previous research has highlighted similar findings in relation to religious practice affecting staff attitudes (Meaney-Tavares & Gavidia-Payne, 2012; Saxe & Flanagan, 2013). Masturbation and homosexuality are areas that have been traditionally observed to create conflict with religious teachings. It is therefore significant that staff attitudes towards PWID on these issues were more conservative. It implies that belief systems have the potential to interfere with their work practices. This area is particularly relevant in Ireland where religious culture is still so dominant.

It was noted that participants that received training reported more liberal attitudes compared to those that had not received training. Previous research has indicated similar findings (Pebdani, 2016).

Finally, staff awareness of the policy documents showed no difference in staff attitudes. However, those that had read the policy documents compared to those that had not, showed more liberal views towards sexuality. This perhaps reflects on the engagement of staff with the

subject area and their willingness to be informed by their services. No previous research has documented this finding.

6.4 Staff Survey

6.4.1 Theme 1 – Unsupported and Frustrated

Staff articulated many thoughts in their feedback, however, the prevailing sense was one of being unsupported and frustrated with their service providers. Staff reported on their frustration of not having available training in their service, this was evidenced by the low numbers of staff that reported receiving training in this study. Previous research has indicated similar low figures for training (Evans et al., 2009; McConkey & Ryan, 2001; Pebdani, 2016; Rushbrooke et al., 2014; Ward et al., 2001). These low training figures for staff are a worrying development, that has a significant impact on all stakeholders. For example, staff in this study spoke about their feelings of fear and anxiety in working with these issues due to being unprepared and under-resourced. With research highlighting that staff are sometimes the only support that PWID have on these matters (Kelly et al., 2009), it is important that staff are comfortable in their ability to work with these situations (Gardiner & Braddon, 2009).

Staff in this study also detailed how they sought their own methods for sourcing training outside of services due to their frustration with the lack of resources. Although this shows engagement on the part of staff, there needs to be caution around this practice. Quality and regulations of these training resources are unknown. As a result, it suggested that services need to take a more direct role in the provision of training. This could be either facilitated internally or through the contracting of specialist training providers who have been sanctioned and appropriately regulated.

Staff reflected that policy and guidance did not replicate what they did in services. This viewpoint has been previously documented in other research (Grace et al., 2017; Hollomotz, 2009). Incongruence with staff practice and organisation principles can impact on service provision. In this position, staff may work under their own initiative, principally guided by their own values and morals (Carnaby & Cambridge, 2002; Ćwirynkalo et al., 2017). Consistency in the governance of issues is a key determinant of not letting standards reduce (Cambridge, 2006).

6.4.2 Theme 2 – Taboo Subject Matter

Twenty years ago, research represented intimate relationships and sexuality for PWID as a taboo subject (McCabe, 1999; McCarthy, 1999; Ryan & McConkey, 2000). This current study reflected the same theme.

Staff reflected on the lack of discussion in this area and how it directly impacted on PWID in their services, reporting that it closed down conversations and made PWID express their sexuality in a hidden manner. They also highlighted the conservative cultural influences in their services, highlighting the past historical restrictions and how these are understood in the present context. They also noted how service and staff member's religious ethos curtailed conversations on this subject. Previous research has recorded similar staff experiences (Lafferty et al., 2012; Ryan & McConkey, 2000). Staff also reported on the absence of 'intimate relationships' in the PWIDs 'care plans'. They reflected how this was an example of services keeping this subject matter off the agenda.

Staff reported that homosexuality was not supported by their services, previous research has reported similar findings (Abbott & Howarth, 2007; Clarke & Finnegan, 2005). However, this is a worrying development in this present study, as today's Ireland is much more culturally accepting of homosexuality than in previous generations. Ireland has legalised homosexuality since 1993, and it was the first country in the world to legalise 'same-sex' marriage by people's vote, in 2015. With national figures of between 4% and 8% of people identifying as homosexual and bisexual in Ireland (O'Brien, 2015) this would imply that PWID rights are being suppressed because of their adult ID service provision.

Staff associations around sexuality in their services were predominantly based on negative interactions. Staff reported that their experiences of sexuality was usually in terms of curtailing "*inappropriate behaviours*" through an individual's 'Behaviour Support Plans'. Previous research has reported similar staff experiences of PWID sexuality in their services (Abbott & Burns, 2007; Lafferty et al., 2012).

Staff also recorded in this "*taboo*" culture, that PWID were fearful of expressing their sexuality. Staff noted that there was a potential for PWID to hide their sexual expression due to being scared of being criticised. Research has documented similar themes of PWID "*fear of being criticised*" in services for expressing their sexuality (Gallagher & Jennings, 2015; Kelly et al., 2009).

6.4.3 Theme 3 – Vulnerability and Education

Staff noted that PWID were vulnerable around issues involving sexuality and relationships. They specifically noted their concerns regarding people with severe and profound ID, with previous research indicating similar themes (Young et al., 2012). This is an understandable viewpoint considering that these people are perhaps the most vulnerable adults in our society.

Staff also expressed their views regarding sexual education. They reflected on the need for PWID to be thought in a recursive manner, engaging with the content consistently, as they recognised some PWID's difficulty to retain information. This viewpoint was interpreted as being both protective in terms safety, but it was also deemed that access to education would lead to greater autonomy for PWID on sexual matters due to improved understanding.

6.4.4 Awareness and Reflection of New Legislation

Staff awareness of the legality of PWID engaging in sexual intercourse with others did not reflect the new 2017 Criminal Act. They referenced the out of date 1993 Criminal Act and their personal attitudes rather than reference to the legislation. However, the reflection of personal attitudes needs to be observed with caution. These were referenced, in the context of an attitude's questionnaire. Staff may have interpreted this question as looking for their opinion on the issue rather than to explicitly state their knowledge in relation to the legal question. However, staff references to the 1993 Criminal Act on this question need to be addressed. It demonstrates that some staff are unaware of the new 2017 Criminal Act. This has significant implications for PWID currently in Adult ID services.

6.5 Integration of Findings

The analysis of both the policy documents and the staff survey shared similar findings, with the staff attitudes questionnaire reflecting another layer of information to these understandings. The following is an integration of these findings.

6.5.1 Welfare and Protection

Welfare and protection were dominant themes that were generated from the policy documents. They were interpreted to construct a 'risk averse' philosophy. These trends were reflected in staff responses on how service providers related to PWID's sexuality. Staff reported that the sexuality of PWID in services was expressed primarily through behaviour support strategies. They outlined how service providers associated PWID's sexuality through "*masturbation in their room*" or through "*dealing with inappropriate behaviours*".

Yool et al. (2003) have noted that service providers prefer options for reducing sexual expression, rather than work with the associated risk. In this study, it appears that services are restricting PWID in their sexuality through their policy's welfare and protection principles. Meanwhile, in service practice, staff member's association of PWID's sexual expression seems to be primarily through behaviour support strategies. This generates the understanding of a risk-averse environment, rather than one that is creating opportunities for PWID to express their sexuality.

Considerable work is needed in this area because there is a potential for these protection and risk minimisations to overshadow PWID rights. This paternalistic viewpoint has the potential to become dominant, and services can 'infantilise' PWID. It is suggested that services need to reflect on sexuality, and what this means to the individual as part of their overall quality of life.

6.5.2 Training

References in the policy documents that "*selected staff*" would receive training implied that training was not a standard for all staff working in the area. This understanding reflects on the service providers and their consideration of this subject matter. It is suggested that by being for "*selected staff*", service providers do not see sexuality of PWID as priority aspect of PWID lives. Otherwise, the provision for this training would stipulate 'all staff'. The low training figures reported in this study reflect that this "*selected staff*" training was evident in practice.

Meanwhile, staff reported feeling frustrated by the lack of training in their services. They expressed their need for more support, guidance and resources. This need was repeatedly expressed by staff responses throughout this study.

In addition, the positive impact of training for staff in this area was documented by the finding that those who had received training demonstrated more liberal attitudes regarding PWID sexuality than those who had not received training. This understanding has a direct impact on service providers and their provision of training for all staff members.

With this understanding, it is suggested that focused training could be applied to individual groups that have been demonstrated to have more conservative attitudes on this area. For example, in this study it was found that staff with lower educational levels demonstrated more conservative attitudes towards sexuality of PWID. By specifically upskilling this group

with training resources, this might potentially increase their attitudes in this area, which would promote better sexual expression for PWID.

Staff also recorded their embarrassment in working with PWID regarding sexuality. Previous studies have highlighted similar themes of staff embarrassment in relation to these subject matters (Lockheart et al., 2009; Wilson et al., 2011) and have highlighted conservative and religious upbringing as possible rationales for these embarrassing feelings (Lafferty et al., 2012). It is suggested that improved access to training and dialogue in services about these subjects would allow for staff to become more comfortable in discussing this subject matter and increase their confidence in dealing with these issues with PWID.

6.5.3 Family

Similar to previous research, both policy documents and staff responses reflected that PWID decisions around sexual issues could be influenced by their family members (Lafferty et al., 2012). As reported, some policy documents stated their support for the family to be informed and have an active role in PWID's sexual decisions. This was subsequently reflected by staff as an area that caused them frustration when they were supporting PWID on these matters. This contrast reflects a concern for PWID rights in adult ID service provision.

This concern needs to be addressed. To offset this and future similar situations, it is recommended that clear policy guidelines and structures to promote the rights of the PWID are required (Fletcher, 2010). As Taylor Gomez (2012) document, clear distinguished boundaries for families around these issues can promote the rights of PWID while also being respectful to families. These strategies would aid staff to support PWID with these matters. In addition, it is essential that service providers build relationships and trust with families around these issues. The creation of good relationships offset the need to automatically refer to guidance, however, it doesn't negate its necessity in practice. It is crucial that there is continued engagement with families in this area, as families hold a position as primary caregiver for many PWID (Lafferty et al., 2012). It is important that families are part of the process in moving forward. However, their opinions and moral standards should be secondary to the rights of their relative. It would appear from the findings of this study that service providers need to be more cognisant of this understanding. PWID's rights are now enshrined in law with Ireland's signature of UNPRCD in 2018. Services need to apply these rights actively in their practice and guidance.

6.5.4 Religion

The explicit representation of a religious ethos in policy was also represented in staff responses. Staff reflected on the religious culture observed in their services and they suggested that its presence was part of the reasoning for a lack of discourse and a conservative philosophy in their services. In addition, it was also represented that staff who practiced religion demonstrated more conservative attitudes on homosexuality and masturbation for PWID compared to those that did not practice religion. These issues are extremely important in terms of service provision.

With service providers needing to adhere to the new 2017 Criminal Act and the recently Irish legislated UNCRPD in 2018. These overt religious references in policy documents, and more importantly, the in-service practice of these value systems, may come into conflict with these newly legislated acts. This is a position that will need to be monitored by all stakeholders involved.

6.5.5 Homosexuality

As noted, the policy documents demonstrated conflicting messages regarding homosexuality. Its reference towards a construct of loneliness and friendship appeared to devalue it as a legitimate sexual expression. Staff also noted similar trends in their experiences when they reported that homosexuality would not be supported in their services. While staff characteristics of older age and practicing of religion were found to be more conservative on issues of homosexuality. All these trends are particularly worrying. PWID are particularly vulnerable to the attitudes and personal beliefs of staff and the supports that are available to them in service providers. Understanding the potential of preconceived prejudices or opinions that staff members may have on the subject can directly impinge of PWID's rights. It is therefore imperative, that policy, practice and staff attitudes in relation to homosexuality are reviewed and monitored.

6.5.6 Education

Both policy and staff responses indicated how Sexual Education were important for PWID. They both highlighted the need for education for all PWID and its importance in reducing their vulnerability. This understanding links with Dukes and McGuire (2009) study as they demonstrated how tailored and sustained Sexual Education packages for the individual can significantly improve the PWID's capacity to make sexual-related decisions. This was a strong

statement from both policy and staff reflecting how Sexual Education can reduce vulnerability for PWID. However, the capacity to fulfil this remit is unclear. With Sexual Education in these services being provided as a reactionary process to inappropriate behaviours, coupled with low training and confidence levels of staff to perform this Sexual Education, the realities experienced might not be reflective of their desires in this regard.

6.5.7 Legislation

Overall, it was noted that the Irish legislation had a significant impact on the provision of care for PWID in their expression of sexuality and relationships. Its dominant position was reflected throughout the policy documents and also in relation to staff responses regarding the legality of sexual intercourse with others. All policies reviewed in this study referenced the 1993 Criminal Act. Considering the effect of this legalisation for PWID in their provision of care, this is an unacceptable situation. This study took place one year and 10 months after the 2017 Criminal Act was legislated into Irish law. Similarly, a substantial representation of staff in this study reported on the 1993 Criminal Act when referencing why PWID legally could not have sexual intercourse with others. Both have negative effects on the expression of sexuality for PWID in services and need to be addressed by services and staff accordingly.

6.6 Ethics Process

As described in the Methodology chapter, significant barriers were posed to this research while applying for ethical approval from the individual service providers. Before applying to each service provider, this research had received ethical approval from the University of Limerick's ethical committee. In addition, numerous steps were taken in liaison with the research supervisor to ensure that the ethical applications would receive a favourable outcome from those involved. However, as evidenced this process was not straightforward; with five separate ethical applications being required. These resulted in an initial refusal and numerous amendments being sought by the service providers.

The researcher cannot draw comparisons with other study's ethical applications to these service providers. The experience in this research may well be indicative of their normal ethical application processes. However, in the noted example, where the service provider's ethical approval was subsequently granted on the condition of the public component of the study being removed; suggests that an ethical issue might not have been the sole reasoning for their initial complete refusal.

Research is a powerful agent in change, and there is a fear that an ethical process that closes or inhibits research from studying phenomenon based on non-ethical issues can damage discourse. 'Relationships and Sexuality' for PWID is an area that requires ongoing research, and as a result, service provider's ethical committees should receive more applications regarding this sensitive topic. It is therefore imperative that ethical committees perform their function of safeguarding participants while not allowing their personal values and opinions to inhibit the process.

6.7 Strengths and Limitations

In interpreting the present findings, a number of strengths and limitations from both the qualitative and quantitative studies need to be considered.

In terms of limitations, it was noted that this review was conducted with five service providers. Although successful efforts were made to engage with the larger service providers from a large geographical range, it is still a relatively small sample size. Similarly, given the relatively small sample size of staff participants obtained during the research it is difficult to indicate how generalisable this study is to all staff and service providers.

Information on staff geographical location and their specific service provider would have added an additional layer to the analysis. It would have enabled a direct contrast between the service provider policy and staff responses. Unfortunately, these details were omitted due to an ethical committee's concern regarding GDPR compliance.

A comparison measure of the staff attitudes to PWID sexuality with the general public would have provided a more robust measure of attitudes. This was originally part of the designed study. However, as above, this was omitted due to an ethical committee's concerns.

The absence of PWID voice in the study was regrettable. Previous research has highlighted the value of PWID participation in these studies (Healy et al., 2009; Kelly et al., 2009; Wilkinson et al., 2014). Unfortunately, due to logistical considerations this was deemed not to be possible. As a researcher, I saw this study, as stage one, with the next stage incorporating the views of PWID through qualitative interviews or focus groups.

Finally, as noted by Braun and Clarke (2012) remaining purely inductive in thematic analysis is a difficult process. They recognise that researchers are part of the analysis, that they bring something to the data that they analyse (Braun et al., 2014). As a researcher I was extremely mindful of this during the process of analysis. I very much followed the recursive

stages as described by Braun and Clarke's thematic analysis (2006). It is suggested that this rigorous process of consistently engaging with the data and being reflective would substantially reduce positionality. However, as a researcher I must acknowledge that my work experiences in the area may have unintentionally permeated the project. These are limitations that all qualitative researchers share, nevertheless they need to be reported on.

The study also had a number of strengths. The use of a mixed methods research design to examine both the policy documents and the staff survey responses was seen as a particular strength. The integration of both qualitative and quantitative design methods led to a comprehensive insight into intimate relationships and sexuality for PWID. The qualitative phase of reviewing the policy documents allowed for an understanding of the construction of 'intimate relationships and sexuality' in service providers. It demonstrated the policy's contradicting viewpoints in relation to rights, values, training, and supportive resources, while also detailing their overarching positions of welfare and protection. In addition, the qualitative methods also allowed for a greater in-depth understanding of staff experiences; in their frustration of being unsupported and of the conservative viewpoints in service providers. These findings were further enhanced with the quantitative section; which saw how certain staff characteristics related to their attitudes and beliefs regarding sexuality for PWID. Overall, the combination of all these research methods provided a more substantial study than either method could achieve individually.

Another perceived strength of this study was that it was conducted online. It was felt that by using this method, staff could answer true to their attitudes and beliefs, rather than give socially desirable responses that can be associated with sensitive subjects, for example, disability and sexuality. By featuring the study online, it also gave reassurances to staff that their responses were completely confidential and anonymous. Whereas, if hard copies of the survey were left in organisations for collection, there could have been fear that management or other staff would see their responses. In addition, the online feature also allowed staff to complete the survey at their own time, once they had the link they could complete it whenever suited them.

Finally, as participants were gathered from a national sample, it allowed for multiple viewpoints from different service providers. This wide geographical representation meant the study was less vulnerable to area-specific difficulties, than if a regional sample had been

examined. This is a particular strength of this study as different service providers have been recognised to have diverging viewpoints on this subject matter (Healy et al., 2009).

6.8 Future Policy Recommendations

Research has documented that service policy cannot answer all the questions that staff face when working with PWID. However, they can provide a framework that outlines organisations structure in terms of the roles and the associated responsibilities of the stakeholders involved (Cambridge, 2006; Lafferty et al., 2012). As a result, based on this study's review, the following recommendations are suggested.

1). it is recommended that all services bring their service policy up to date with the current 2017 Criminal Act. The 1993 Criminal Act had a significant influence on the reviewed policy documents in this study. As this legislation no longer applies to this jurisdiction, the removal of its guidance would be welcome.

2). it would be strongly recommended that a 'national policy' be created. It is suggested that this would circumvent the potential for historical, cultural and religious belief systems that have been observed to operate in these organisations. Bypassing local service providers would create a national template to be followed. This would allow for greater clarity for all service providers, staff and most importantly PWID themselves. All PWID in Ireland would be represented by a common ethos and therefore equality in this regard could be monitored by national regulatory bodies rather than based on the services that PWIDs are affiliated with.

3). there is a need for further reference towards 'positive risk' regarding PWID and sexuality. A dominant narrative of protection and welfare serves only to put restrictions on PWID in these services. As stated in Brown and McCann (2018) policies need to focus on a human rights-based approach and improve the lives of PWID by focusing on their aspirations around sexuality. This study would support this viewpoint and advocate for a similar philosophy in future policy construction.

4). it is suggested that these policies should be practical in their construction to make them more accessible for staff. They should reflect the day-to-day practices to have the maximum change in services (Brown & McCann, 2018). Policy documents should also include reference to PWID socialising, dating and the use of the internet. It should be stated that this is not an advocacy for a prescriptive format. Rather, it is suggesting practical examples with references that could be further elaborated upon in training would be of most benefit.

Finally, it is suggested that the formation of these policy documents should take a ‘bottom up’ approach; incorporating PWID involvement. They are the people being represented, yet as listed as authors of the reviewed policy documents, their voice is significantly absent. Previous research has highlighted similar suggestions, with Gallagher and Jennings (2015) detailing that service providers should partner with PWID to develop and implement policies and guidelines on all aspects of sexuality and personal relationships. This would empower PWID to be active agents in their own lives.

6.9 Clinical Practice and Future Research Recommendations

In addition to the above policy suggestions, this study also highlighted areas for recommendations for clinical practice and future research. Similar to previous research, these recommendations are multifaceted in their design, and they incorporate suggestions for service providers, staff and PWID (Ćwirynkalo et al., 2017; Lafferty et al., 2012).

1). the provision of training for all staff employed in Adult ID services is essential. Training removes uncertainty and replaces it with clarity for both staff and PWID. It can provide parameters for staff to work in, reduce their preconceived attitudes and viewpoints by providing a consistent approach (Cuskelly & Bryde, 2004; Yool et al., 2003). Furthermore, staff need to be made aware of legislation and policy updates. Information should be made freely available to staff in this regard. A suggestion of mandatory reading of policy documents could allow staff to be more informed on the subject matter.

In addition, due to the attitudes detailed in this study it is suggested that there is a requirement for training to be mindful of staff attitudes and incorporate reflective practice in its approach. Future research in this area could incorporate the design of staff training. It is suggested that ‘active research approaches’ where staff inform and guide the training through focus workshops would allow for practical input while also remaining cognisant to the existing literature.

2). it is suggested that similar training modules could be used with PWID family members. This would be beneficial in terms of creating dialogue, developing relationships and also setting boundaries that outline service providers primary role in supporting PWID. It is crucial that there is continued and respectful engagement with families in this area. They hold a primary position as a caregiver for many PWID and their input is valued in their overall quality of life (Lafferty et al., 2012).

3). Sexual Education needs to be delivered in an appropriate way for PWID. In Ireland, young PWID that attend ‘Special Schools’ fall under the similar guidelines as those at primary level education. Under this system, Relationship and Sexuality Education does not go beyond a primary level, which has a strong focus on personal care and relationships rather than sexuality itself (Nolan, 2018). This means that this grouping does not receive age appropriate sexual education. Appropriate Sexual Education is required for all PWID, and this needs to be reviewed in these schools.

4). as noted for policy, services and staff need to be cognisant not to become risk averse in relation to these issues. A focus on protection can limit opportunities for PWID on these matters (Lafferty et al., 2012). It is suggested that staff and services could become more mindful of the potential for these restrictions by auditing their own individual practices. In this regard, it is suggested that ‘relationships and sexuality’ for PWID are ascribed in practice as quality of life goals for all services. The proposed construction and the practical application of these standards is another avenue for future research.

5). it is suggested that policies and staff member’s existing focus of the vulnerability of PWID need to be addressed through service provision. Research demonstrates that improved Sexual Education for PWID can offset potential vulnerabilities by increasing their capacity in these areas. In this study, services were strong to reflect the need for all PWID to receive these educational resources, in a flexible manner that was reflective of individual needs. However, the viability for staff to impart this education was not reflected in the staff responses, due to their own lack of training in the area. It is therefore incumbent of services to upskill staff to provide these educational resources.

6). as identified in the policy documents, there were no reference to socialising, dating and the use of the internet. This is an underexplored concept with this population. Future research and service practice could consider reviewing and implementing strategies around these issues. As Chadwick, Wesson, and Fullwood (2013) postulate PWID could benefit from the use of the internet to reduce isolation and develop social relationships. This could improve all types of contact not just the expression of their sexuality (Darragh, Reynolds, Ellison, & Bellon, 2017). Furthermore, in earlier studies, PWID have documented their wishes to have a dating agency for PWID (Healy et al., 2009). This an interesting concept. One that is perhaps more relevant today, as changes towards community living have resulted in PWID spending less time with other PWID, which has resulted in PWID limiting their potential ‘pool’ for

partners and relationships (Thompson, 2019). It is suggested that future research and practice should consider these concepts.

7). it is suggested that services need to be doing more in relation to making staff and PWID they support become comfortable about talking about sexuality and relationships. For example, the creation of 'sexual awareness weeks', open access training and workshops for staff and PWID, and a general openness and approach for improved communication in this area can all aid in reducing the '*taboo*' nature of this subject matter. This '*taboo*' subject matter was exemplified in this study by the absence of intimate relationships in PWID 'care plans'. It is therefore contended that future research and service practice should consider the inclusion of these sections in these documents. It is suggested that this would both stimulate dialogue in organisations and ultimately make it part of standard practice.

Finally, it is acknowledged that part of this study was a review of the policy documents themselves, and although this gives an important insight into these services, it is not, and could not be a full-scale service review. As such, certain features of the culture and ideology have been lost in translation. Future research should try and explore this lived experience, and perhaps further reflect on the religious, cultural and current service practices as defined in this study.

6.10 Summary

This study found that service policy's statements for the supportive and positive expression of sexuality for PWID were far too often later contradicted in their texts through their language, and narrative. These policy documents delivered conflicting messages on rights, values, training and supportive structures. These were interpreted to leave the reader confused and unsure of their practice. In addition, there was a dominant focus on welfare and protection, that was deemed to restrict PWID's sexual expression.

Staff experiences of current services reported their frustrations about being unsupported; in training, in dealing with family members, and also with the *unclear* and *restrictive* content of policy guidance. They also expressed the current conservative nature of services with reference to the lack of discussion and the impact that religion had on PWID's expression of sexuality. Staff discussed the barriers to sexual orientation and their service provider's focus on negative associations of sexuality, through 'behaviour supports plans'. Staff also noted the vulnerability of PWID and expressed their need for Sexual Education.

Meanwhile, staff attitudes to sexuality were found to be more conservative for staff that were older, actively practiced their religion, had a lower educational level, were not trained in the area, and had not read their service policy on ‘relationships and sexuality’.

From the findings of this study, it is evident that service providers need to deliver improved resources in terms of policy, guidance and training. Both service providers and staff need to become more proactive in supporting ‘positive risk’ and understand that protection of PWID cannot be the sole function of their roles (Bates et al., 2017). In addition, the impact of staff attitudes to sexuality for PWID needs to be monitored; with supports being provided for staff member’s reflective practice on these matters.

6.11 Conclusion

As cited in the rationale for this study, it was ten years ago when there was a series of Irish publications on this subject matter (Evans et al., 2009; Gardiner & Braddon, 2009; Healy et al., 2009; Kelly et al., 2009). However, this present study demonstrates that effectively very little has changed for PWID in the intervening years.

It becomes imperative to lay down the marker and ensure that researchers are not investigating this same area in another ten years. It is, therefore, vital that service providers and staff progress forward in the interest of PWID. Under societies construction of human rights, PWID are required to have the ability to express their sexuality freely. It is essential that society aids them, in fulfilling this right. It is with this understanding that this research is a call to action; it is a call for change.

6.12 Personal Reflection

Overall, I feel that this research was extremely worthwhile. It set out to explore the current attitudes and views of both service providers and staff in relation to their work in the area of intimate relationships and sexuality for PWID. In doing so, it successfully addressed a gap in the literature regarding Adult ID service provider’s construction of ‘Relationship and Sexuality’ policy. It also allowed staff members to articulate their current viewpoint on the subject matter.

I am proud of this study. It was an active piece of clinical research and as such, it has had its pitfalls and frustrations. However, I hope that its findings will generate dialogue in the field and ultimately improve the quality of life for PWID that are supported by Adult ID service providers.

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Appendix A Recruitment Poster

MEMO

Please find details below of a research study being conducted by Andrew Deffew, Clinical Psychologist in Training (HSE Mid-West and the University of Limerick).

Andrew's doctorate research is looking at the area of intimate relationships and sexuality for adults with intellectual disability. His research has been approved by our local ethics board and has also received ethical approval from the University of Limerick (ehsresearchethics@ul.ie).

Call for Research

This is a brief outline of the proposed research. More information regarding the study and issues outlining confidentiality can be accessed via the link for the questionnaire. If you have any further questions, please contact Andrew on the email provided below.

Title of Study: Intimate Relationships for Adults with an Intellectual Disability: Exploring the views of Adult ID Service Providers and their staff members

Purpose of the Study: Adults with ID can be reliant on service providers and staff members support for many aspects of their life, including intimate relationships. They may seek support in terms of education and guidance, and/or support for expressing their sexuality. As a result, service providers' and staff members' viewpoints on intimate relationships are extremely important to those they support.

This research project will investigate these viewpoints. It is a national study which aims to review Adult ID Service Provider's intimate relationship policies and staff members' attitudes, views, opinions, and beliefs on the topic. This research will add to the existing literature and have an impact on relationship and sexuality service policy. It will also help staff to be better supported in this area.

Confidentiality: All questionnaire data will be anonymous and confidential. There will be no personal identifiers. No individual information recorded will be shared with the service that you work in. This is an opt-in study. You can withdraw from the survey at any point without any consequence.

What you have to do: complete an anonymous questionnaire online that will last approximately 15 minutes in duration. Please copy the provided link into your search engine and complete. All staff are encouraged to participate individually.

Questionnaire Link

<https://ww2.unipark.de/uc/AndrewDeffew/>

QR Code



Many thanks,

Andrew Deffew, Clinical Psychologist in Training

Email - andydeffew@gmail.com

www.linkedin.com/in/andydeffew-000

Appendix B Consent Sheet

Title: Intimate Relationships for Adults with an Intellectual Disability: Exploring the views of Adult ID Service Providers and their staff members.

Consent to participate in the survey:

I have read and understood the Information Leaflet about this research project. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that I don't have to take part in this study and that I can opt out at any time. I understand that I don't have to give a reason for opting out and I understand that opting out won't affect my future medical care.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I am aware of the potential risks, benefits and alternatives of this research study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I consent to take part in this research study having been fully informed of the risks, benefits and alternatives.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I give informed explicit consent to have my data processed as part of this research study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I give permission for material/data to be stored for <i>possible future research related</i> to the current study <i>without further consent being required</i> but only if the research is approved by a Research Ethics Committee.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

If you do not want to be part of the survey, then you can simply decline to complete this questionnaire.

If you choose to complete this survey, your consent is implied by its completion.

If you have any further queries please contact the lead researcher, Andrew Deffew.

Thank you for your time.

Andrew Deffew,
Clinical Psychologist in Training

Email - andydeffew@gmail.com

Appendix C Participant Information sheet

Intimate Relationships for Adults with an Intellectual Disability: Exploring the views of Adult ID Service Providers and their staff members.

Principal Investigator - Andrew Deffew, Clinical Psychologist in Training, HSE and the University of Limerick - email: andydeffew@gmail.com

Co-Investigator – Dr Barry Coughlan, Director of Clinical Psychology Programme, University of Limerick – email: barry.coughlan@ul.ie

The purpose of this study is to explore Adult ID staff members and the general public's thoughts around supporting adults with an intellectual disability with intimate relationships and their sexuality.

This is an academic project, in partial fulfilment of the Doctorate in Clinical Psychology; as such the findings will be used for the researcher's PhD thesis. Findings will also be submitted to conferences and peer review journals. There is no funding source to this study.

What you have to do: complete an anonymous questionnaire online

All data from the questionnaires will be anonymous and confidential. There will be no personal identifiers. This is an opt-in study. Completing the questionnaire will indicate consent. No individual information recorded will be shared with the service that you work in. You can withdraw from the survey at any point without any consequence.

If you agree to take part, the questionnaire will last approximately 10 to 15 minutes in duration.

It is hoped that the findings from the study will help staff in their role in supporting adults with an intellectual disability by helping to inform the development of staff training programmes.

This survey has been approved by the University of Limerick's Ethics Committee. If you should require any further information, they can be contacted via email ehsresearchethics@ul.ie.

Data Protection

Data is being processed under articles 6 and 9 of General Data Protection Regulations 2016 articles - 6 (1 f) processing of information for legitimate interests and 9 (j) processing is necessary for archiving purposes in the public interest, scientific or historical research purposes in accordance with Article 89.

1. All data is completely anonymised with no identifiers. Researcher named in this study will not have access to any of your personal information as recruitment will come from in-service administrators.
2. Anonymised data will be view by the primary investigator and the co-investigator named. In addition, as this is an academic exercise, external examiners may also wish to view the data.
3. Digital data will be stored on an encrypted USB in a locked filing cabinet in the researcher's home. In line with best practice, data will be destroyed in 7 years.
4. All data is anonymised, as such encrypted data, if a data breach were to occur there would be no identifying information in relation to the participants.
5. As data is anonymous, participants will not be able to withdraw their consent to participate or have information corrected or deleted after the have completed the survey. There are no identifiers in the information, so it would be impossible to withdraw their survey responses. However, participants will have every opportunity to withdraw from the study at any stage without consequence.
6. For the same reason as above, participants will be unable to request their survey responses after completion.
7. If participants wish, they have a right to lodge a complaint with the Data Protection Commissioner, they can contact by email at: info@dataprotection.ie

If you have any further queries please contact the lead researcher, Andrew Deffew.

Email - andydeffew@gmail.com

Appendix D Questionnaire

1. Please indicate if you are: Male Female Other

2. Age Range: <25 years 25-35 years 36-45 years 46-55years 56-65+ years

3. Please indicate highest level of education: (drop down)

Secondary School

Third Level Cert/Dip (Level 5/6

Undergraduate (level 7/8)

Postgraduate (Level 9/10

4. Personal Religion affiliation:

5. Do you practice your religion? Yes No Sometimes

6. How long are you working in this Adult Intellectual Disability Service (years and months):

7. Current Job Title:

Please consider the individual(s) that you support for the majority of the time

8. Gender of the individual(s) that you support for the majority of the time?

Male

Female

9. Level of ID of the individuals that you support the majority of the time (as defined by their care notes?)

Mild

Moderate

Severe

Profound

Sexuality Questions

1. Are people with an intellectual disability allowed in law to have sex with other people with an ID?
Yes No Don't know

1. Are people with an intellectual disability allowed in law to have sex with people that do not have an ID?
Yes No Don't know

2. Do you think that people with an intellectual disability can make proper decisions about having sexual relations?
Yes No Don't know

3. Do you think that staff should support people with intellectual disabilities to make decisions about their sexual relationships?
Yes No Don't know

4. How comfortable are you with working with issues of sexuality and intellectual disability?
Yes No Don't know

5. Are you aware if there is a current Service Policy regarding relationships for people with ID in your service?
Yes No Don't know

6. Have you read a Service Policy regarding relationships for people with ID in your service?
Yes No

7. Are relationships included in the "care plans" for the people you support?
Yes No Don't know

8. Are intimate (sexual) relationships included in the "care plans" for the people you support?
Yes No Don't know

9. Have you received Training regarding sex and intimate relationships for people with ID?

Yes No Don't know

10. Did you find this training beneficial?

Yes No Don't know

11. How long ago was this training? (in months):

12. In your experience, can you explain how service users express their sexuality?

13. What would be helpful for you in relation to the issues of relationships and sexuality for the people that you support?

Appendix E Attitudes to Sexuality Questionnaire

(Adults with an intellectual Disability) Adapted from Cuskelly & Gilmore, 2007)

1.	With the right support people with intellectuality disability can rear well-adjusted children.	Strongly disagree	0---1---2---3---4---5	Strongly agree
2.	Provided no unwanted children are born and no-one is harmed, consenting adult people with an intellectual disability should be allowed to live in a heterosexual relationship.	Strongly disagree	0---1---2---3---4---5	Strongly agree
3.	Consenting adult people with an intellectual disability should be allowed to live in a homosexual relationship if they so desire.	Strongly disagree	0---1---2---3---4---5	Strongly agree
4.	It is best to wait for a girl or woman with ID to raise questions about sexuality before discussing the topic with her	Strongly disagree	0---1---2---3---4---5	Strongly agree
5.	People with ID have less interest in sex than do other people	Strongly disagree	0---1---2---3---4---5	Strongly agree
6.	If people with ID marry, they should be forbidden by law to have children	Strongly disagree	0---1---2---3---4---5	Strongly agree
7.	People with ID should be allowed to engage in non-sexual romantic relationships	Strongly disagree	0---1---2---3---4---5	Strongly agree

8.	Medication should be used as a means of inhibiting sexual desires in people with ID	Strongly disagree	0---1---2---3---4---5	Strongly agree
9.	Masturbation should be discouraged for people with ID	Strongly disagree	0---1---2---3---4---5	Strongly agree
10.	Discussions on sexual intercourse promote promiscuity in people with ID	Strongly disagree	0---1---2---3---4---5	Strongly agree
11.	People with ID should only be permitted to marry if either they or their partners have been sterilised	Strongly disagree	0---1---2---3---4---5	Strongly agree
12.	Masturbation in private for people with ID is an acceptable form of sexual expression	Strongly disagree	0---1---2---3---4---5	Strongly agree
13.	People with ID typically have fewer sexual interests than other people	Strongly disagree	0---1---2---3---4---5	Strongly agree
14.	Generally, people with ID are able to make distinctions between sexual thoughts and sexual actions	Strongly disagree	0---1---2---3---4---5	Strongly agree
15.	People with ID are unable to develop and maintain an emotionally intimate relationship with a partner	Strongly disagree	0---1---2---3---4---5	Strongly agree

16.	Sex education for people with ID has a valuable role in safeguarding them from sexual exploitation	Strongly disagree	0---1---2---3---4---5	Strongly agree
17.	In general, sexual behaviour is a major problem area in management and caring for people with ID	Strongly disagree	0---1---2---3---4---5	Strongly agree
18.	Sexual intercourse should be permitted between consenting adults with ID	Strongly disagree	0---1---2---3---4---5	Strongly agree
19.	Group homes or hostels for adults with an intellectual disability should be either all male or all female, not mixed	Strongly disagree	0---1---2---3---4---5	Strongly agree
20.	Care staff and parents should discourage people with ID from having children	Strongly disagree	0---1---2---3---4---5	Strongly agree
21.	It is best not to discuss issues of sexuality with girls with ID until they have reached puberty	Strongly disagree	0---1---2---3---4---5	Strongly agree
22.	People with ID have the right to marry	Strongly disagree	0---1---2---3---4---5	Strongly agree
23.	It is a good idea to ensure privacy at home for people with ID who wish to masturbate	Strongly disagree	0---1---2---3---4---5	Strongly agree

24.	Whenever possible, people with ID should be involved in the decision about their being sterilised.	Strongly disagree	0---1---2---3---4---5	Strongly agree
25.	Sexual intercourse should be discouraged for people with an intellectual disability	Strongly disagree	0---1---2---3---4---5	Strongly agree
26.	Advice on contraception should be fully available to people with ID whose level of development makes sexual activity possible	Strongly disagree	0---1---2---3---4---5	Strongly agree
27.	People with ID are more easily stimulated sexually than people without ID	Strongly disagree	0---1---2---3---4---5	Strongly agree
28.	Marriage between adults with ID does not present society with too many problems	Strongly disagree	0---1---2---3---4---5	Strongly agree
29.	Sterilisation is a desirable practice for people with ID	Strongly disagree	0---1---2---3---4---5	Strongly agree
30.	Sex education for people with ID should be compulsory	Strongly disagree	0---1---2---3---4---5	Strongly agree
31.	Masturbation should be taught to people with ID as an acceptable form of sexual expression in sex education courses	Strongly disagree	0---1---2---3---4---5	Strongly agree

32.	Marriage should not be encouraged as a future option for people with ID	Strongly disagree	0---1---2---3---4---5
		Strongly agree	
33.	People with ID should be permitted to have children within marriage	Strongly disagree	0---1---2---3---4---5
		Strongly agree	
34.	People with ID have stronger sexual feelings than other people without an ID	Strongly disagree	0---1---2---3---4---5
		Strongly agree	

Appendix F Letter of Ethical Approval



19th September 2018

Dear Barry, Andrew

Thank you for your amended Research Ethics application which was recently reviewed by the Education and Health Sciences Research Ethics Committee.

The recommendation of the Committee is outlined below:

Project Title: 2018_09_11_EHS Intimate Relationships for Adults with an Intellectual Disability: Exploring the views of Adult ID Service Providers, Staff members and the General Public.

Principal Investigator: Barry Coughlan

Other Investigators: Andrew Deffew

Recommendation: Approved until December 2019.

Please note that as Principal Investigator of this project you are required to submit a Research Completion Report Form (available on website) on completion of this research study.

Yours Sincerely

Drew Harrison PhD, FISBS

Chair, Education & Health Sciences Research Ethics Committee

Associate Professor in Sports Biomechanics

Department of Physical Education and Sports Science

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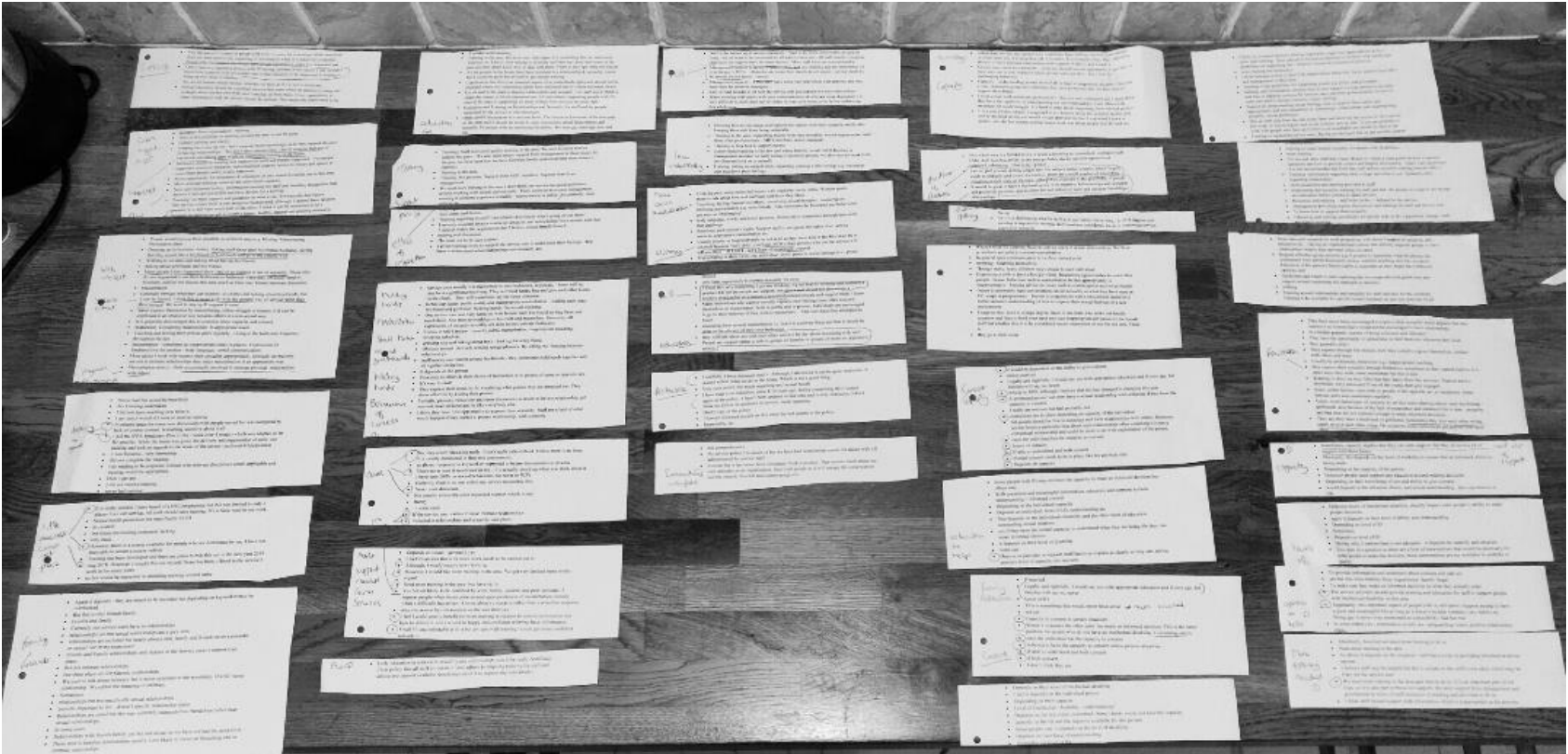
Appendix G Example of refining codes towards themes for Policy Documents

Codes	Refined Codes	Sub-Themes	Themes
Equality for PWID – part of the person	Equality for PWID	Equality	Rights of PWID
Love and intimacy language	Love language	Autonomy	Values
People First language	People First language	Sexual Rights and Expression	Training and Education
Autonomy of PWID	Autonomy of PWID	Legislation	Welfare and Protection
Using Legislation to frame values	Legislation promoting values	Stated Values	Supporting Structures
Openness to talk education	Empowerment	Use of Language	
Empowerment	Homosexuality rights	Sex Education PWID	
Rights about their decision	Protection of PWID	Staff and Family Training	
Caring	Welfare	Clarity of Content	
Protection of PWID	Vulnerability – level of ID	Vulnerability and Risk Minimisation	
Capacity – level of ID	Risk aversion – language	Capacity and Consent	
Vulnerability	Training supports	Service Structures	
Staff Responsibility and roles of duty	Education supports - capacity	Practicality of delivery	
Staff reflective capacity	Outside Contributors		
Service Responsibility	Hierarchy mgmt. structures		
Risk aversion – language	Legislation barriers-		
Training supports	Pulls apart legal position		
Education supports	Pregnancy in service		
Outside Contributors	Deprivation of liberty – pornography		
Hierarchy mgmt. structures	Family restriction of autonomy		
Practical guidance	Homosexual restriction		
Families involved in decisions	Christian values – ethos		
Accessibility of documents	Contraception		
document length	Document Accessibility		
repetition of language	Practical guidance –absence		
Deprivation of liberty – pornography	repetition - language		

Appendix H Sample of Thematic Analysis for Policy Documents

Service Policy	Coding	Subthemes	Themes
<ul style="list-style-type: none"> • People with intellectual disabilities have the same rights as all other members of society. They have a right to make decisions about how they live. • People with intellectual disabilities are entitled to be safe from personal exploitation, bullying, harassment and from all forms of abuse, including sexual abuse. <p>United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993) states that -</p> <ul style="list-style-type: none"> • States should promote the full participation of people with disabilities in family life, and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood, and that persons should not be denied the opportunity to express their sexuality. <p>Standard 2.8 of the HIQA Standards for Residential Services for People with Disabilities</p> <ul style="list-style-type: none"> • The individuals' privacy and dignity are respected at all times, and with particular regard to expressions of intimacy and sexuality. 	<p>Rights as equal citizens Rights about their decision making</p> <p>Protection and welfare Safety from abuse and exploitation</p> <p>Using Legislation to frame support Inclusion – Rights Sexual expression values</p> <p>Rights – privacy and dignity</p>	<p>Equality</p> <p>Vulnerability and Risk Minimisation</p> <p>Legislation</p> <p>Sexual Rights and Expression</p>	<p>Rights of PWID</p> <p>Welfare and Protection</p> <p>Values</p> <p>Rights of PWID</p>

<p>XXXXXXXXXX will provide the following supports -</p> <ul style="list-style-type: none"> • XXXXXXXXXXXX will promote the rights of its adult service users in the area of sexuality and relationships. • XXXXXXXXXXXX will help our service users to develop friendships and to engage in personal, intimate, loving and sexual relationships at levels which are: <ul style="list-style-type: none"> ○ Appropriate for their understanding, capacity to consent and to avoid exploitation. □ XXXXXXXXXXXX will help service users to avail of advocacy services as requested by themselves or their family. □ XXXXXXXXXXXX will provide or help service users access education and training which helps them develop their ability to make informed decisions, to develop social relationships and to understand and develop their sexuality. □ XXXXXXXXXXXX will provide or enable access to training for staff and families relevant to the support required for the implementation of this policy. 	<p>Promotion of Rights</p> <p>Supporting friendship Love and intimacy language Support sexual relationships</p> <p>Protection and safety</p> <p>Support from outside agencies</p> <p>Sexual Education and skills building, helps with decision making and sexuality</p> <p>Providing Training staff Providing training Family</p>	<p>Sexual Rights and Expression</p> <p>Stated Values Use of Language</p> <p>Capacity and Consent</p> <p>Service Structures</p> <p>Sex Education PWID</p> <p>Staff and Family Training</p>	<p>Rights of PWID</p> <p>Values</p> <p>Welfare and Protection</p> <p>Supporting Structures</p> <p>Training and Education</p> <p>Training and Education</p>
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Appendix I Example of refining codes towards themes for staff survey

Codes	Refined Codes	Sub-Themes	Themes
Supports needed	Lack of guidance - unclear	Policy and Guidance	Unsupported and Frustrated
Poor/limited resources	Restrictive	Training	
understaffed	Difficult position dealing with families	Dealing with Families	Taboo Subject Matter
Vulnerability - level of ID	Family restrictions	Uncomfortable and Anxiety	
negative behaviours	Need for improved education	Lack of Discussion	PWID Vulnerability and Access to Education
Need for early education	Staff frustration re: training	Conservatism and Religion	
Service user - hide it away	Sourcing training outside service	PWID Perspective	
Culture and society	Staff anxiety	Negative associations of Sexuality	
frustration around service guidelines	Level of ID - vulnerability	PWID Vulnerability	
Anxiety and fear	Masturbation in bedrooms	Improved access to Sex Education	
solo expression - masturbation	Need for training		
identification that sexuality is natural	Difficult position dealing with families		
capacity of person	Family restrictions		
Taboo subject	Not supported by services with family		
how to respond	Taboo subject matter		
family – supersedes autonomy of individual	PWID understanding of sexuality in services		
Need for Sex education	Education protections against abuse		
confidence issues -	Reactive strategies		
ongoing and open discussion	Older staff restrictive attitudes		
cope as parents?	Ongoing sexual education – life long		
responsibility to educate service user	Staff embarrassment		

Appendix J Factor structure of the ASQ-ID

Factor Item	
Factor 1: Sexual rights	<p>2. Provided no unwanted children are born and no-one is harmed, consenting people with an ID should be allowed to live in a heterosexual relationship</p> <p>5. People with ID have less interest in sex than people without an ID (R)</p> <p>10. Discussions on sexual intercourse promote promiscuity in people with ID (R)</p> <p>13. People with ID typically have fewer sexual interests than people without an ID (R)</p> <p>15. People with ID are unable to develop and maintain an emotionally intimate relationship with a partner (R)</p> <p>16. Sex education for people with ID has a valuable role in safeguarding them from sexual exploitation</p> <p>17. In general, sexual behaviour is a major problem area in management and caring for people with ID (R)</p> <p>18. Sexual intercourse should be permitted between consenting people with ID</p> <p>19. Group homes or hostels for adults with an intellectual disability should be either all male or all female, not mixed (R)</p> <p>22. People with ID have the right to marry</p> <p>26. Advice on contraception should be fully available to people with ID whose level of development makes sexual activity possible</p> <p>28. Marriage between adults with ID does not present society with too many problems</p> <p>32. Marriage should not be encouraged as a future option for people with ID (R)</p>
Factor 2: Parenting	<p>1. With the right support people with ID can rear well-adjusted children</p> <p>6. If people with ID marry, they should be forbidden by law to have children (R)</p> <p>11. People with ID should only be permitted to marry if either they or their partners have been sterilised (R)</p> <p>20. Care staff and parents should discourage people with ID from having children (R)</p> <p>25. Sexual intercourse should be discouraged for people with an intellectual disability (R)</p> <p>29. Sterilisation is a desirable practice for people with ID (R)</p> <p>33. People with ID should be permitted to have children within marriage</p>
Factor 3: Non-reproductive sexual behaviour	<p>3. Consenting adults with ID should be allowed to live in a homosexual relationship if they so desire</p> <p>9. Masturbation should be discouraged for people with ID (R)</p> <p>12. Masturbation in private for people with ID is an acceptable form of sexual expression</p> <p>23. It is a good idea to ensure privacy at home for people with ID who wish to masturbate</p> <p>31. Masturbation should be taught to people with ID as an acceptable form of sexual expression in sex education courses</p>
Factor 4: Self-control	<p>8. Medication should be used as a means of inhibiting sexual desires in people with ID (R)</p> <p>27. People with ID are more easily stimulated sexually than people without ID (R)</p> <p>34. People with ID have stronger sexual feelings than other women (R)</p> <p>Note. (R) Reverse scored items.</p>

